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Person-Centered Chronic Illness Management in the Nursing Home

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Person-Centered Chronic Illness Management in the Nursing Home

by

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Dissertation

Presented to the Faculty of the Graduate School of

The University of Texas at Austin

in Partial Fulfillment

of the Requirements

for the Degree of

Doctor of Philosophy

The University of Texas at Austin

August 2013

Dedication

To the sun, the moon, and the stars, *aka*, Michael, Julia, and René.

Acknowledgements

I am most indebted to my advisor and dissertation chair, Sharon A. Brown, PhD, RN, FAAN. I could not have had a more consistent source of inspiration and support. To impart knowledge, provide guidance, offer opportunities, and ensure progression in academia in a lighthearted and confidence-building manner is a true gift. I was privileged to be a part of Dr. Brown's research team for four fun-filled, educationally-packed years. Her research inspired me, her expectations encouraged me, and her work ethic awed me.

I would also like to especially thank my methodology advisor and committee member, Tracie C. Harrison, PhD, RN, FNP. My interest in qualitative research was sparked, kindled, and kept aflame through her educational expertise and research leadership. She provided me with not only a qualitative research experience, but a rich data set from which to conduct the secondary analysis included in this work. She was always available for consultation, advice, and direction in my research and career endeavors. Her insights on older age, disability, and chronic illness deeply inspired me and often brought a heartfelt tear or two to my day.

Additionally, I would like to thank Dr. James Goodwin and Dr. Yong-Fang Kuo for graciously sharing their expertise in grant writing and gerontological research. They made it possible for me to assist in the collection of data in support of their research at The University of Texas Medical Branch in Galveston and allowed me to use this data to conduct the secondary analysis which became the final project of this dissertation work.

I am also grateful for the expertise and guidance of Dr. Gayle Acton, Dr. Ruth Anderson, and Dr. Cherie Simpson, my dissertation committee members. Dr. Acton has provided me with constant support and encouraged me to pursue a well-rounded

knowledge of gerontology and its political, social, and clinical implications. Dr. Anderson, my long-distance long-term care research mentor, gave me much needed incentive to continue my conviction to conduct research in nursing homes. Her work at Duke University and life-time devotion to the improvement of long-term care illuminated a path filled with purpose and dedication. I have followed that path to this point and plan to continue on in my future work. Dr. Simpson's insights and counsel regarding care of the aging and their families has helped me better articulate the intent and findings of my work and her teaching expertise and respect from her students have greatly inspired me.

I would like to thank Dr. Linda Yoder for her unending support and mentorship. She was the inspiration to my initial pursuit of a doctorate degree and her example, and unwavering confidence and faith in my abilities, has carried me through. Dr. Carole Taxis has been my educator role model, a true joy in the classroom. I can only hope that someday my students will appreciate me as much as I appreciate her. Dr. Glenda Joiner-Rogers has provided me with unlimited gerontological clinical insights, research support, and ongoing guidance since the moment I walked in her door. She jumped in to help me with both feet and I am incredibly indebted to her. I would also like to thank Dr. Alexandra Garcia, Dr. Adama Brown, Mary Winter, and Charla Carrington, my co-research team members, for their constant support, encouragement, and laughter. There are countless others who have helped me along the way including Dr. Deborah Volker, Fran Sonstein, and Dr. Sharon Horner who have listened to my research ideas and provided me with expert direction and unique perceptions.

I thank the alumni and supporters of The University of Texas at Austin School of Nursing who have helped to fund my graduate education through scholarships and endowments. I would like to thank the attorneys and staff of Bowman and Brooke LLP

for their encouragement and support and for allowing me to maintain a very unorthodox work schedule throughout this endeavor.

I would like to send a group hug to the many friends I have made along the way and to friends from before this experience, who have stuck by me, despite my inattention. Definitely, we are a rare breed, and yes, a strange breed, but all, so very special. I have received more love and support from my friends than I can possibly express in words. They have carried me through the many ups and downs in this journey with laughter and high hopes, and for that I will be forever grateful.

This work would not have been possible without the study participants who gave their time and consideration toward the goal of improving the quality of life for those living out their lives with chronic illness in nursing homes. I would like to thank each resident and family member participant and the many nursing facilities, administrators, health care providers, and staff who greeted the conduct of research in nursing homes with open arms and open hearts.

Finally, I would like to express my deep gratitude to my family for the support, tolerance, and unconditional love given to me over the years. My parents have always listened to me, prayed for me, and encouraged me, and they were truly my inspiration for this work. My parents-in-law never failed to ask about my progress and gifted me with the laptop that made this work possible. The strength of my sister's faith and pride in me helped push me through. My wonderful children possess an indescribable power to make anything seem possible. Their support has meant the world to me. And, saving the best for last, my husband is simply the best thing that has ever happened to me and he proves that every day.

Preface

The following document is a dissertation in a non-traditional format titled, "Person-centered Chronic Illness Management in the Nursing Home." It will be based upon four projects: a quantitative review of the literature, a pilot ethnographic study, a qualitative review of the literature, and a secondary analysis of existing qualitative data. This work enabled an integrated synergy of methods used to understand the phenomenon of person-centered management of chronic illness in the nursing home setting.

The dissertation has five chapters: Chapter One presents an overview of the dissertation work. It provides background information surrounding person-centered chronic illness care in the nursing home setting, a description of the sensitizing framework used in this work, a summary of an ethnographic pilot study conducted by this researcher, and a description of the research design and methodology used to conduct the final project, a secondary analysis study. It also includes a justification for conducting the secondary analysis and a description of the anticipated results, and expected limitations of the final study.

Chapter Two presents a literature review of which large portions have been previously published as, "Diabetes Management in the Nursing Home: A Systematic Review of the Literature," co-authored by this researcher (Garcia & Brown, 2011), reporting results from a systematic review of the literature on the management of type 2 diabetes in the nursing home setting. This chapter provides a review of studies conducted over the last decade, concerning the management of type 2 diabetes in the nursing home setting. Type 2 diabetes is a chronic illness affecting more than one-third of the nation's nursing home residents (Centers for Medicare and Medicaid Services (CMS), 2010). Management of this chronic illness includes daily monitoring, treatment, prevention

measures, and follow-up by the patient, medical provider, facility care provider, and often, family members.

A search of ten medical and psychological databases yielded a total of 20 studies published in the last decade, meeting the stated criteria, and addressing care of this chronic illness in nursing homes. The review describes the studies in terms of design, method, findings, and implications for improvement in management of chronic illness and improvement of nursing home resident outcomes. It found that most studies on this topic primarily described the frequency of various management practices such as blood glucose monitoring, foot checks, and dietary restrictions. Adherence to clinical practice guidelines, such as those released by the American Medical Directors Association (AMDA; 2008), was also frequently measured and found to be quite rare in practice. Few of the studies related management strategies to health outcomes and the voice of residents and families and their preferences for diabetes treatment in this setting were absent. This review presents a summary of the strengths and weaknesses of the literature surrounding management of a prevalent chronic illness in the nursing home setting. It revealed a gap in the nursing home chronic illness management literature regarding the involvement of the resident in management decision-making and self-care activities.

Chapter Three is a manuscript titled, “Involvement of Older-aged Adults in Chronic Illness Care Decisions: A Metasynthesis” (Garcia & Joiner-Rogers, 2013, Manuscript in preparation). This work is a synthesis of qualitative literature that seeks to provide an emic description, or a rich, personal, description from the point of view of the older-aged person, of the meaning of involvement in routine or daily chronic illness care decisions and the factors that may influence involvement for older aged individuals. The study was conducted in the context of person-centered care and patient autonomy in chronic illness care for the older-aged patient. Seven studies comprised the sample, two

of which were conducted in nursing homes. Themes were derived from a plethora of terms in the data describing loneliness and loss. From the patient/resident's perspective, being involved in health care decisions meant being validated as a person, improved well-being, and feelings of importance. Not being involved conveyed feelings of powerlessness and low self-esteem. Lack of time spent with patients by medical providers emerged as the overarching theme that tied all the studies together. The findings of this study illuminated the benefits and possible harms that accompany involvement or non-involvement of older-aged persons in their chronic illness decision-making and supported the need for further research into the opportunities available for resident involvement and how these opportunities can be enhanced in this setting.

Chapter Four reports the findings from a secondary analysis study in manuscript format. This study was based on previous qualitative work (Harrison, Garcia, Goodwin, & Kuo, 2012, Manuscript in preparation) describing medical provider selection from the perspectives of five groups of stakeholders in the nursing home setting: residents, family members of residents, advanced practice registered nurses, physicians, and nursing home administrators. The secondary analysis viewed the data through the lens of a chronic care management framework and aimed to describe how stakeholders viewed opportunities for resident involvement in chronic illness care and what they perceived to be important qualities in an advanced practice registered nurse that enhanced person-centered chronic illness care in this setting. The combination of the perspectives from these stakeholders who play a vital role in providing and planning the daily health care management regimes of this population aided in providing a more complete picture of resident involvement. Chapter Five summarizes the implications and conclusions of the four projects making up this dissertation research.

In summary, Chapter One provides an overview of the background and significance of these projects, summarizes an ethnographic pilot study conducted to support this work, and describes the design and methods used to conduct the final project, the secondary analysis study. Chapters Two and Three, both in manuscript format, present reviews of the quantitative and qualitative literature, respectively, supporting the secondary analysis research. Chapter Two is largely drawn from a published report co-authored by this researcher. Chapter Four presents the findings of the secondary analysis study in manuscript format; and Chapter Five is a final summary of the implications and conclusions of the four projects and the overall dissertation research.

Person-Centered Chronic Illness Management in the Nursing Home

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The University of Texas at Austin, 2013

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The Baby-boom generation, a major contributor to an unprecedented increase in older-aged people, is known for its zest for life and autonomy. Boomers are predicted to enter nursing homes in record numbers with multiple chronic illnesses and person-centered health care expectations. The purpose of this work was to describe current chronic illness management practices in nursing homes focused on person-centered (resident-directed) care and involvement of residents in health-related decision-making and self-care activities. Four projects were undertaken to accomplish this objective: (1) a systematic review of the quantitative literature regarding the management of type 2 diabetes, an exemplar chronic illness; (2) a synthesis of the qualitative literature describing chronically ill, older-aged adults' perceptions of chronic illness care decision-making; (3) an ethnographic pilot study describing the meaning of having type 2 diabetes to nursing home residents; and (4) a qualitative descriptive study of secondary data describing nursing home stakeholder perceptions of opportunities for resident involvement in chronic illness decision-making and self-care activities. Wagner's Chronic Care Model, modified for the nursing home, was the sensitizing framework for this research. Twenty studies met criteria for the systematic review, which described a lack of adherence to clinical practice guidelines and rare inclusion of the resident and

family in management practices. The synthesis of 7 qualitative studies revealed 4 themes: (1) *Being recognized because I matter*; (2) *Awareness of importance*; (3) *Empower through connections and opportunities*; and (4) *Time is precious*. Cognitively capable older-aged adults described benefits from involvement in health care decisions and harm from non-involvement. They perceived inadequate time spent with health care providers as a major determinant of involvement. The pilot ethnography included 3 residents. Findings revealed a perception of few diabetes management choices but many unspoken resident preferences. The qualitative descriptive secondary analysis study included 5 residents, 7 family members, 8 advanced practice registered nurses, 5 physicians, and 6 administrators. Stakeholders perceived many opportunities for resident involvement in decision-making and self-care, but described as many limitations. Findings indicated a shortage of health care providers and differing stakeholder ideas of purpose and goals restricted resident involvement. Clinical, research, and policy implications were discussed.

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Chapter 1: Overview

INTRODUCTION

There are approximately 1.5 million people living in US nursing homes; most are above the age of 69 years and afflicted by one or more chronic conditions, such as diabetes, arthritis, and cardiovascular disease (CMS, 2012). This number is expected to increase substantially over the next few decades (Vincent & Velkoff, 2010), due to the aging of the Baby-boom population and because people are living longer and acquiring more chronic illnesses (American Hospital Association (AHA) & First Consulting Group (FCG), 2007). These chronic and disabling conditions leading to dependence in activities of daily living are among the strongest predictors for nursing home admissions (Gaugler, Duval, Anderson, & Kane, 2007).

Prevention of chronic illnesses in older age is a high priority on today's health care agenda (Institute of Medicine (IOM), 2001) as is ensuring the provision of quality chronic illness care in the community and in long term care settings. A hallmark of high quality long term care is focus on the individual's needs and preferences for daily care in order to maximize self-determination and self-care, at least to the level of the individual's capacity and desire, improving health outcomes and quality of life (Koren, 2010). This concept is also known as person-centered care. In a recent review of studies regarding the management of type 2 diabetes, a prominent chronic illness in the nursing home setting, Garcia and Brown (2011) found a gap in the literature with respect to the inclusion of the patient's preferences in the plan of care. Advocates of person-centered care in nursing homes strive to promote optimal quality of life and health outcomes through care focused on and directed by the patient or resident, to the extent they desire. The nursing home differs from other health care settings however, in that it is challenged to not only provide

high quality medical and psychiatric care, but to provide it in a home-like environment, as free of hospital regimentation as possible. This is necessary because the nursing home is not only where a resident receives health care but also, and primarily, a place where he or she lives, sometimes for a finite amount of time but often, for the rest of his/her lifetime.

A “home” is well described by Judith Carboni (1990) as providing an individual with a sense of identity, connectedness, privacy, autonomy, power, safety, predictability, and freedom, whereas she defined “homelessness” as the opposite or negation of home. She described the experience of home as a relationship or interaction with the environment. She and others (Molony, 2010) have found this intimate relationship with daily surroundings provided a critical connection for residents to the meaning and quality of life. Carboni described elderly nursing home residents as homeless because they had no intimate relationship with their environment; it was beyond their control. Unlike a hospital setting, where a temporary loss of autonomy is considered a small price to pay in exchange for medical care and expertise, loss of autonomy in the nursing home setting over a long period of time may lead to loss of identity, and can be mentally and physically devastating (Shawler, Rowles, & High, 2001).

Thus, providing a high degree of resident autonomy in daily living activities, which often include chronic illness care activities, is a high priority in nursing homes striving to provide person-centered care. Person-centered care and freedom of choice with respect to daily activities of living, such as eating, bathing, and dressing, have been studied in the nursing home setting (Kane, Caplan, Urv-Wong, Freeman, Aroskar, & Finch, 1997; Rodin & Langer, 1977; Simmons, Rahman, Beuscher, Jani, Durkin, & Schnelle, 2011) as have critical care choices in this setting (Funk, 2004; Kayser-Jones, 1995) and choices regarding end of life decisions (Berger & Majerovitz, 1998; Lawrence,

2009; McParland, Likourezos, Chichin, Castor, & Paris 2003). Yet, despite the high incidence of multiple chronic illnesses and disabilities in nursing home residents, few studies have addressed resident freedom of choice regarding daily chronic illness care and health-related activities, such as monitoring, treatment, and other activities to prevent or treat symptoms and complications that can greatly affect quality of life in this setting.

At least 20% of nursing home residents are higher functioning, in that they are able to function more independently than others, both cognitively and physically, suggesting they are capable of possibly returning to community settings (McNabney, Wolff, Semanick, Kasper, & Boult, 2007). This also implies that some nursing home residents may be capable of being involved in their chronic illness plans of care and self-management activities. Funk (2004) found that 43% of older aged chronically ill nursing home residents sampled in Canada preferred to be fully involved in making independent decisions regarding their health and daily activities. Findings from an ethnographic pilot study conducted by Garcia and Harrison (2011) suggested that some nursing home residents have unspoken preferences for their chronic illness plans of care and felt their preferences were not important to the management plan. Consistent recognition of these preferences and encouragement to stay involved at the highest level possible and desired by the individual seems vital to providing person-centered care with the potential to preserve resident self-confidence, identity, and dignity, and possibly to improve health outcomes and quality of life.

In a recent meta-synthesis of qualitative studies, Garcia and Joiner-Rogers (2013) described older aged persons' views on involvement in daily medical care decision-making. Themes emerging from this metasynthesis suggested that involvement of older-aged persons in everyday health care decisions promoted patients' perceptions of being recognized as unique persons of value whose opinions mattered. Lack of involvement led

to feelings of worthlessness, powerlessness, and isolation, which may, in turn, contribute to disinterest in personal health and well-being. This work supports the need for further research in person-centered care for the older-aged adult and illustrates the importance of involving capable and interested patients in chronic illness management decisions that affect their health and quality of life.

Consistently providing person-centered health care places many demands on the nursing home health care team including organizing care, providing evidence-based care, and spending ample and quality time with the patient to ensure their needs are being met. All of this is quite a tall order for nursing homes faced with a shortage of gerontological medical specialists (Caprio, Karuza, & Katz, 2009; Goolsby, 2011), high nursing home staff turnover (Seavey, 2004), and decreasing rates of reimbursement from federal and state governments for health care services (The Alliance for Quality Nursing Home Care, 2012). Medical care providers in the nursing home setting consist primarily of physicians, advanced practice registered nurses (APRNs; including nurse practitioners and clinical nurse specialists), and physician assistants. Physicians are decreasing in number and the latter two, mid-level practitioners, are increasing in number (Intrator, Feng, Mor, Gifford, Bourbonniere, & Zinn, 2005).

There appears to be little motivation for medical care providers to specialize in nursing home care given the disproportionately small numbers of them in this field (Levy & Kramer, 2005; Levy, Palet, & Kramer, 2007). The discussion regarding the shortage of qualified medical practitioners in long term care settings is beyond the scope of this paper. However, because the unique, holistically heavy care needs of nursing home residents fit the overall holistic care philosophy of the nursing profession, it seems prudent to assert that the APRN is in an ideal position to meet the needs of this very vulnerable and often disadvantaged population.

Research has indicated that APRN's are a valuable and key resource in providing consistent, person-centered health care to residents of nursing homes (Kappas-Larson, 2008; Abdallah, 2005). Thus, one of the aims of the secondary analysis study in this work focused on nursing home stakeholders' perceptions of the qualities APRNs may possess that can enhance the involvement of capable and interested residents in chronic illness care. It is recognized that other members of the medical care provider team also play important roles in meeting the needs of this population, and this researcher plans to conduct studies that examine these other key roles in this setting in the near future.

Study purpose

The overall purpose of this dissertation work was to describe chronic illness management practices in the nursing home setting focused on the involvement of older-aged nursing home residents in decision-making and self-care activities within their plans of care. This was accomplished through the presentation of four projects: (1) a systematic review of the literature regarding the management of an exemplar chronic illness, type 2 diabetes, in the nursing home setting; (2) a pilot study of resident preferences regarding diabetes management in the nursing home; (3) a meta-synthesis of the qualitative literature regarding the meaning of involvement in chronic illness decision-making from the perspective of older-aged adults in the community and in nursing homes; and (4) a secondary analysis of data describing nursing home stakeholders' perceptions of opportunities for resident involvement in chronic illness management decision-making and self-care activities and how personal and professional qualities possessed by the APRN may enhance resident involvement.

Background

Person-centered care

Person-centered care is an inspiring philosophy, defined as a holistic approach to care which empowers an individual to be involved in health care decisions to the degree desired by offering choices and negotiation in an atmosphere of mutual respect (Morgan & Yoder, 2012). Person-centered care is best described as a concept of partnership between the health care provider and the receiver of care, where each respects the contributions, experiences, values, and goals of the other (National Aging Research Institute, 2006). Its history dates back to the 1940's when Carl Rogers based his psychological model on the assumption that no one can make decisions for another individual, but the individual, himself (Rogers, 1965). Historically, health care systems have operated using a medical model in which a person with a disease or problem condition received treatment based primarily on the condition, with little emphasis on the individual characteristics of the person who had the condition. This has slowly begun to change and more health care providers are taking a more biopsychosocial view of the person, considering the physical symptoms, psychological well-being, social environment, and preferences of the person, i.e., a more holistic approach. Person-centered care requires that patients are provided with the information necessary (options and risks) to make informed decisions regarding their health care, if they desire to do so.

The outcomes of person-centered care, or of providing patients with information, choices, and decision-making power regarding their health care treatments, are mixed. Patient involvement in health care decisions and self-care activities has been shown to improve health outcomes and care efficiency (Stewart et al., 2000; Kaplan, Greenfield, & Ware, 1989); increase adherence to treatment regimens (Kim, Kaplowitz, & Johnston, 2004); increase patient satisfaction (Williams, Weinman, & Dale, 1998) and to have an

impact on patients' feelings of self-respect and confidence (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Belcher, Fried, Agostini, & Tinetti, 2005). On the other hand, Tak, Ruhnke, and Meltzer (2013) recently conducted a study in a Chicago medical center and found that patients who preferred to participate in making decisions regarding their health care had on average, longer hospital stays and increased hospitalization costs, implying, at least, worse financial outcomes, and possibly, worse health outcomes.

It is important to recognize that current definitions of person-centered care include different concepts and nuances within those concepts, depending on the source. For example, the concept of involving a patient by helping them to understand their choices and the reasons behind provider recommendations is generally a well-understood concept of person-centered care; however, going farther to involve patients in decision-making, allowing them to make informed choices, and following through on their preferences is a more complicated, and possibly less-accepted, concept (Gleckman, 2012; Daley, 2012). It is essentially placing control of the treatment regimen and its outcomes in the hands of the patient (Berwick, 2009). The complexity of defining person-centered care and its possible implications and outcomes, make its systematic evaluation and/or implementation quite challenging.

Person-centered care in the nursing home. The long term care system began considering major reform to improve quality of care in the early 1980's when a consumer advocacy group, The National Citizens' Coalition for Nursing Home Reform, led focus groups of nursing home residents in discussions regarding the definition of "quality" (Burger et al., 2009). This spurred the IOM to publish a 1986 report entitled, *Improving the Quality of Care in Nursing Homes*. This, in turn, led to major legislation in 1987, which added the Nursing Home Reform Act to the Omnibus Budget Reconciliation Act (OBRA). This new law mandated many nursing home reforms aimed at improving

quality of care and quality of life in nursing homes and made nursing homes the only sector of the health care industry to legally require person-centered care (Koren, 2010).

Person-centered care in long term care, includes concepts such as: maintaining a home-like environment, enabling residents to determine or direct their own care, and empowering front-line staff (such as clinical nurse assistants), who spend the most amount of time with nursing home residents (Koren, 2010). Although the Nursing Home Reform Act was enacted 25 years ago, few facilities have wholly adopted these measures; and many of the same problems that prompted the person-centered care movement still exist (Levenson, 2009; U.S. Government Accountability Office, 2005). Nursing homes moving toward adoption of a person-centered care philosophy often offer much more than the superficial appearance of a home environment; they strive to provide care incorporating the individual preferences of the resident as well as the care provider. The goal is to promote resident autonomy, preserve dignity, and empower the front line care provider to assist the resident in self-directed care and activities.

Elements of person-centered care in the long-term care setting have been described by many (Crandall, White, Schuldheis, & Talerico, 2007; Kitwood, 1997; Mead & Bower, 2000; Morgan & Yoder, 2012; Sloane et al., 2004). The general elements found in the literature include: (1) holism, or consideration of the person as a whole set of physical, mental, emotional, intellectual, and spiritual aspects apart from illness (Morgan & Yoder, 2012); (2) personhood, or valuing and preserving the uniqueness and individual value that each person possesses when he/she enters a nursing home and how it affects the view of illness (McCormack, 2003; Kitwood, 1997); and (3) autonomy, or maintenance of the person's right to choose his/her life course and health care plans (Talerico, O'Brien, & Swafford, 2003). Table 1 lists elements of person-centered care with operational definitions explaining how the element was conceptualized

in the nursing home setting. Person-centered care refers to transforming traditional (medical-model) nursing home settings into "home" environments where residents determine or direct their own care (Koren, 2010). Outside the nursing home, this may be referred to as "integrative medicine" (Maizes, Rakel, & Niemied, 2009); within the nursing home, it is often referred to as "culture change" (Burger et al., 2009).

The IOM Report (2001) emphasized the need to close the quality chasm of today's health care systems, referring to the large gap between services that people need and services that our system is prepared to provide. The IOM (2001) stressed that persons with chronic diseases needed patient-centered care where the patient is the source of control. People hospitalized for acute care needs expect a certain amount of loss of control or autonomy over their lives during a hospital admission; they accept this for the good of their health and because they know it is temporary. Nursing home residents, on the other hand, are not patients (Welford, Murphy, Wallace, & Casey, 2010). They most typically have chronic care needs in this setting and their stay in a nursing home is not generally temporary, but rather, for the rest of their lives. Thus, according to the IOM (2001), their care should be person-centered and they should be in control, if they so desire. Although, medical care in nursing homes is required for virtually all residents, and is often provided with minimal nursing staff (Seavey, 2004) and inadequate economic resources (Grabowski, Angelelli, & Mor, 2004), it must still meet high clinical standards, such as AMDA's clinical practice guidelines for type 2 diabetes management (2008), which include individualizing care and including resident preferences in the plan of care.

Examples of resident-centered care or culture change in nursing homes can be found in Eden Alternative model homes, Green House models, and the Wellspring model, all of which strive to provide a more home-like setting, and a team-care approach to improve resident quality of life without decreasing health outcomes or increasing costs

(Mueller, 2008). Evidence supporting the effectiveness of these models is mixed but encouraging and definitely warrants the need for continued research, especially regarding the role of the nurse in NH culture change and resident outcomes (Mueller, 2008).

The current nursing home population

People are living longer due largely to advances in health care as well as healthier lifestyles (AHA & FCG, 2007). For example, smoking has decreased in men from 51% in 1965 to 23% in 2005 and in women from 33% to 19% (National Center for Health Statistics, 2006). People are dying less often from heart disease and the five-year cancer survival rate has increased by 16% over the last 20 years from 50% to 66% (American Cancer Society, 2007). In 2009, life expectancy in the US was 76 years for men and 80.9 years for women; additionally, women reaching age 65 could expect to live 20.3 years longer while 65 year old men, could expect to survive an additional 17.6 years (National Center for Health Statistics, 2011). A longer lifespan leaves more time to acquire illness and disability and require assistance.

The number of 65 year olds entering a nursing home is predicted to double between 2010 and 2020, so that by 2020, 46% of all 65 year olds will need nursing home care at some point before they die and 9% of 65 year olds will spend 5 years or longer there (Spillman & Lubitz, 2002). Fifty-two percent of women aged 65 or older in 2020 will need nursing home care and 14% of 65 year old women will live there for 5 years or longer (Spillman & Lubitz, 2002). With literally one of every two 65 year olds predicted to spend at least some time in a nursing home in the next 10 to 30 years, it is inevitable that nursing home systems and philosophies of care will personally, and likely intimately, affect everyone in the very near future.

An average 75 year old suffers from three chronic conditions and takes 5 prescription medications (Merck Institute of Aging & Health (MIAH), the Centers for Disease Control and Prevention (CDC), and the Gerontological Society of America (GSA), 2004). According to CMS (2012), the most common chronic diseases currently affecting US nursing home residents include: hypertension (68%), depression (45%), dementia (39%), diabetes (31%), arthritis (24%), chronic lung disease (19%), heart failure (19%), and stroke (16%). Although almost 40% of current nursing home residents are diagnosed with some form of dementia, 54% can make themselves clearly understood and 50% clearly understand others (CMS, 2012). The March 2012 Minimum Data Set (MDS) also documented that 69% of current nursing home residents were the primary respondents regarding preferences for daily activities and 77% were able to participate in care assessment and goal setting. These statistics suggest that nursing home residents are capable of exercising autonomy with regard to their daily plans of care and self-management; but questions remain as to whether they desire involvement in health care planning, current opportunities for them to be involved, and whether they are encouraged to be involved. These questions were qualitatively explored in this dissertation work.

The "Silent Generation." Residents of nursing homes today are largely from the generation known as the "Silent Generation," born between 1922 and 1945. The origin of the generation's name could be related to growing up during a time when it was commonly said, "children should be seen and not heard," or could stem from being a young adult during anti-communism activities when it was dangerous to express an opinion about anything, thus the trend toward … silence (Thornton, 2009). This generation also known as "The Veterans," lived through World War II, the Great Depression, the Korean War, FDR's New Deal, and racial segregation. Their core values have been described as: loyalty, sacrifice, hard work, and respect for authority

(University of Iowa, 2009). At the workplace, they tended to be dedicated, consistent, and hard-working; they adhered to rules, were patient, and respected and conformed to authority.

Generally, this group's members do not complain, are often complacent when they disagree with something, see things mostly as "black and white," and assume "no news is good news" (Thornton, 2009). These characteristics may carry over into how they deal with health care issues. This generation may be uncomfortable questioning health care providers, or may not even consider questioning them, because they respect the providers' expertise and authority. They may not complain if unhappy with care. They may not consider alternative therapies or medications unless asked to do so and they may assume they do not need to concern themselves with health care decisions or choices, unless asked.

Providing person-centered care for this generation may require health care providers to go the extra mile to ensure that these patients are adequately informed about their conditions, that all treatment options are presented, and that if capable and desired, each person is encouraged to participate in his/her health care decisions and management. Providing person-centered care in nursing homes is important for the current residents of nursing homes and for the residents of the future, who promise to be greater in number and possibly more vocal in their demands of the health care community.

The Future Nursing Home Population

The "Baby-boom" generation. Long-term care is being provided to approximately 12 million people today and by 2050 it is expected that the number of people in long term care will more than double, to 27 million (Kaye, Harrington, & LaPlante, 2010). This enormous growth in need for long-term care services has been

primarily fueled by the extremely large “Baby-boom” generation (born between 1946 and 1964) who began turning 65 in 2011. Due to the aging of the Baby-boomers, the number of persons over the age of 65 will rise from 40.2 million in 2010 to 88.5 million in 2050 or 20% of the total US population (US Census Bureau, 2008). The oldest old (aged 85 years and above) will likely have the highest need for nursing home admission and their numbers are expected to increase by 25% in 2030 and by 126% in 2050 (US Census Bureau, 2008). Thus, despite efforts to decrease the population in nursing home facilities by facilitating their move back into private homes (Kaiser Commission, 2011), it is virtually inevitable that, because of the sheer numbers of elderly, nursing home census will grow, likely at an unprecedented rate.

The first of the Baby-boom population reaching the age of 65 years in 2011 marks the beginning of at least 40 years of heavy growth in the older-aged sector of the American population. Every day between 2011 and 2029, 10,000 Baby-boomers will celebrate their 65th birthday (Cohn & Taylor, 2010). And celebrate they will, because Baby-boomers, more than previous generations, do not feel turning 65 is even close to entering old age, which they consider to be 72 (Cohn & Taylor, 2010). The 79 million member Baby-boom generation promises to re-define old age, as most feel at least nine years younger than their stated age and plan to delay retirement for as long as possible (Cohn & Taylor, 2010).

The Baby-boom generation has several key characteristics that distinguish it from other generations and promise to challenge the current health care industry. The boomers lived through post WWII economic prosperity; they saw and participated in civil rights movements including Black civil rights and women’s civil rights. Many of this generation, thanks to the generation before, grew up with a sense of security, which left them room to explore, grow, and accumulate wealth. In the workplace, they are team-

oriented but also thrive on personal gratification. They tend as a group, to value youth, money, and health. They like to be involved and strive to be "where the action is" (University of Iowa, 2009).

This generation of older aged individuals will, as a group, possess higher education and be more aware of clinical issues than any other elder population in US history (Healthcare Intelligence Network, 2006). Close to 90% of boomers are high school graduates and 57% have attended college (U.S. Census Bureau, 2006). They will be more technologically savvy and proficient in the use of the web and social networking in order to meet their health information needs. Currently, 53% of older aged Americans use the internet and e-mail and one-third of those aged 65 and older use social networking such as Facebook (Zickuhr & Madden, 2012). Being better informed will allow this generation to be more demanding of high quality care and more discerning of where they choose to receive care and from whom. Also, unlike the previous elder generation, Baby-boomers are currently the wealthiest group in the country. They currently possess 75% of the nation's financial assets and much more disposable income than their parents. If they are able to maintain their wealth well into their elder years, they will be in an even better position to make demands of the health care community.

But given their numbers, education, technology, and wealth, what exactly is it that boomers will want? Currently, Baby-boomers are working, and many are caring for and obtaining care for their aging parents. They are learning what today's health care system has to offer older aged, physically, and mentally challenged adults. Many are making decisions for their parents and beginning to consider what they would want and not want when they reach this age. According to a report by AHA and FCG (2007), boomers are more likely to have participated in advanced directives and have plans for eventualities such as loss of cognition, end of life wishes, and palliative care. They are more active

than previous generations, so it is likely they will remain active longer and desire health care services that focus on mobility and independence. They are interested in complementary and holistic medicine (American Association of Retired Persons (AARP), 2011), so it is to be expected that they will demand health care that is varied, individualized, and innovative (AHA & FCG, 2007).

Boomers, like generations before them, will try to remain as independent as possible for as long as possible, but given the chronic diseases that have already begun to affect some and the later ages that they are expected to live, it is quite likely that this generation too, will become residents of nursing homes, and in large numbers. In keeping with their generational personality, it is likely that this cohort of residents will expect to remain active participants and/or have consistent involvement in their health care plans. They will demand individualized, efficient, and innovative care and they will do everything in their power to ensure they get what they want. It could be argued that they have already begun working toward this end, not only for their sakes but for the sakes of their parents currently in long-term care situations. Baby-boomers are pushing to the forefront the need for health care systems to provide person-centered, cost-efficient, high technology elder care. Thus, it is imperative that current levels of individualization and resident involvement in nursing home medical care be examined as well as the issues that influence resident involvement for this generation and the generation to come. This dissertation work qualitatively addressed these issues from the perspectives of various nursing home stakeholders, including nursing home residents.

Growing ethnic diversity, and possibly disparity, in the nursing home

The Hispanic population in the US is known to have several health disparities (Angel & Angel, 2006). They are the fastest growing ethnicity among the older aged

population. Currently, they represent 7% of the US population aged 65 and over, and by 2050, their numbers are predicted to increase to nearly 20% (Villa, Wallace, Bagdasaryan, & Aranda, 2012). Hispanics have lower mortality but higher morbidity than most, yet at the same time, they have a higher prevalence (Angel & Angel, 2006) and higher hospitalization rate (Beard, Ghatrif, Samper-Ternent, Gerst, & Markides, 2009) for certain chronic conditions such as diabetes and obesity. These chronic conditions are likely to be long-standing and undiagnosed since middle-age, which increases the likelihood of severe complications, disability, and need for long term care (Villa et al., 2012).

Hispanic resident nursing home admissions have increased by 54.9%, while there has been a 6.1% decline in the overall nursing home admission rate from 1999 to 2008, chiefly led by non-Hispanic White people whose admissions have dropped by 10.2% (Feng, Fennell, Tyler, Clark, & Mor, 2011). Many older-aged Caucasian people have opted for assisted living facilities or have taken advantage of Medicare waivers or new opportunities for home-based care through the Health Care Affordability Act. The option to forego or delay nursing home admission is often only available to the fairly wealthy, largely discounting the great majority of economically and educationally disadvantaged Hispanic, African-American, and other minority elders.

Additionally, older-aged patients from minority groups and from lower socioeconomic backgrounds are less likely to be involved in health care decision-making and self-care activities (Tak et al., 2013; Benbassat, Pilpel, & Tidhar, 1998). Thus, it is possible that increasing numbers of Hispanics in nursing homes may further increase health disparities by increasing some of the possible adverse effects suggested to be associated with less involvement, such as powerlessness and lower self-esteem. This work will not specifically address the issue of possible increased health disparities for

Hispanic people in the nursing home due to the lack of representation of Hispanics in the secondary analysis sample; but it will lay the groundwork for future work on examining these issues in the nursing home setting.

Chronic Illness in Older Age

Approximately 62% of persons aged 50 to 64 years reported they had at least one chronic condition (Collins, Davis, Schoen, Doty, & Kriss, 2006) and about 8.6 million or 10% of those aged 65 and above, report multiple chronic conditions. This number is expected to increase to almost 37 million or more than 60% of the older adult population by 2030 (AHA & FCG, 2007).

Chronic diseases, including heart disease (30% of all deaths), cancer (23%), and stroke (7%) have now become the leading causes of death in the United States, replacing infectious diseases, e.g. tuberculosis and pneumonia, that caused the majority of deaths in the past century (MIAH et al., 2004). According to an annual report generated by the CDC (2009), heart disease, cancer, and chronic respiratory diseases were the three leading causes of death for older aged adults in 2009, followed by stroke, Alzheimer's disease, and diabetes. AHA and FCG (2007) predict that by 2030, the number of people in the US with diabetes will rise from 30 million, in 2007, to 46 million, translating to about one in every four people over the age of 65. Arthritis is predicted to increase from 46 million affected persons today to 67 million by 2030, or one out of two older aged people. Obesity is expected to affect one in every three older adults by 2030, adding to the numbers of those with diabetes, heart disease, and hypertension.

The most frequent and likely most damaging cause of injury for older adults is falls. Living longer, being more active, being burdened with disease, and taking more medications will increase the number of falls and the likelihood of decreased mobility

and independence in the future for the upcoming older adult generation (CDC, 2007). Presently, more than one-third of older adults fall each year with up to 30% sustaining fractures; close to 350,000 hip fractures occurred in 2000 with twice this amount predicted during the year 2050 (Fuller, 2000). Given the high probability that the coming generation of older adults will face multiple chronic diseases and disabilities, it is imperative that health care providers and facilities prepare for their needs.

A survey conducted of health care organizations and providers to assess the impact of the surge in the older adult population on the health care system found that more than half of the sample felt that obesity-related illness will be the greatest health issue for older adults in the future, followed closely by the related conditions of diabetes and hypertension (Healthcare Intelligence Network, 2006). They also ranked areas in the health care arena needing improvement in order to meet the health demands of the future: "prevention and early detection of disease" was ranked first and "chronic care needs" ranked second. They ranked "chronic care needs" first on the list to have the greatest cost impact on health care in the future, "prevention and early detection" second, and "supportive care, such as in-home, community and institutional locations," was ranked third (Healthcare Intelligence Network, 2006, p. 3).

Quality of life with chronic illness. Hospitals are preparing for a large influx of patients with chronic disease needs and daily strides are made toward helping people to "age in place" or receive home care services from their private homes after hospital discharge, in order to remain independently living at home for as long as possible (AHA & FCG, 2007). The goal to remain independent for as long as possible stems from the need to maintain a good quality of life for as long as possible, and preserving autonomy and independence is central to this goal. Person-centered care in nursing homes also strives to maintain optimal quality of life through the maintenance of autonomy and the

preservation of dignity. The concept of health-related quality of life includes physical health, mental health, emotional health, and social functioning. (U.S. Department of Health and Human Services, 2010). As older adults age, their perceptions of a good or excellent quality of life decrease. The 2001 National Health Interview Survey found that 43% of people aged 65 to 74 years reported very good or excellent health, compared with 34% of 75 to 84 year olds, and only 28% of those aged 85 and older (MIAH et al., 2004).

Quality of life for older aged people living with multiple chronic conditions is at risk as they enter their seventies and eighties largely due to increasing disability that accompanies chronic illness combined with fairly intense health regimens necessary to maintain optimal health. The "Baby boom" generation is known for valuing above all else, independence, choice, and health, whereas the previous generation, in nursing homes now, tend to value authority and the importance of rules and order (Healthcare Intelligence Network, 2006). This difference in life philosophy will present additional challenges for the health care industry as they try to meet the person-centered needs of Baby-boomers with multiple chronic illnesses and disabilities combined with high expectations and demands for high quality of care and quality of life.

Stakeholders in Nursing Homes

Stakeholders are persons who are interested in (and have a stake in) an enterprise, or can affect or be affected by actions taken by that enterprise or organization (Merriam-Webster, 2013). Major stakeholders in the nursing home setting that have an effect upon or are affected by the care provided by nursing homes include: residents, their family members, medical and nursing care providers, and facility administration, to name only a few. According to a report by Harahan, Stone and Shah (2009), responsibilities and functions of key professional stakeholders in nursing homes (clinical nurse assistants

(CNAs), nurses, physicians, and administrators) are many and include: administration of medications and clinical treatments; oversight and direction of medical care provided by physicians either solely or in collaboration with APRN's; and operation of the facility, ensuring compliance with federal and state regulations provided by facility administrators. Stakeholders interviewed in the parent study included a sample of those who directly affect medical care provided in the nursing home: physicians, APRN's, and administrators; as well as a sample of those who are directly and/or indirectly affected by the care provided: residents and family members. Although CNAs are considered to be extremely important stakeholders in nursing home person-centered care, they were not sampled by the parent study, because the focus of that study was primarily on the provision of medical care and the selection of medical care providers.

Tester and colleagues (2004) found that care providers, visitors (family), and other residents could be instrumental in enhancing a resident's sense of self, sense of home, sense of control, and quality of life. Medical professional stakeholders in nursing homes differ from medical health professionals in other health care settings in that they must provide high quality health care while at the same time ensuring their patient's (resident's) sense of personal space and autonomy (Welford, Murphy, Wallace & Casey, 2010). Balancing these tasks can be difficult for care providers (Jakobsen & Sorlie, 2010), especially when residents are in frail physical health and many have some degree of cognitive impairment (Kasper & O'Malley, 2007). Also adding to the difficulty is the requirement placed on nursing facilities to meet a myriad of state and federal regulations designed to improve quality of care but that tend to encourage automated and rigid decisions by facility personnel that may detract from residents' autonomy and quality of life (Colon-Emeric, Plowman, Bailey, Corazzini, Utley-Smith, Ammarell … & Anderson, 2010). Finding a balance in receiving health care may also be difficult for

residents and their families who often find themselves struggling to maintain autonomy while having to accept that they are chronically ill and dependent on others in many ways (Rodin, 1986).

It is because of this unique and often trying situation in this setting that the perceptions of this group of stakeholders are essential to providing a rich description of resident involvement in medical and/or health care provided in the nursing home. In this setting, the medical professional stakeholders are intertwined in not only the health care of these residents, but in the day-to-day lives and decisions of residents and their families. Their ideas, beliefs, and actions are a part of the environment and culture in which nursing home residents live. What medical professional stakeholders think, do and say may in some way affect what nursing home residents and their families think, do, and say. Thus, including all these perspectives and considering them as a whole will enhance and provide a more balanced, and complete description of resident involvement in health care planning and self-care.

The APRN in the nursing home setting. Due to the high demand for medical care in the nursing home and a shortage of nursing home physicians, APRN's are assuming a greater role in this setting. APRN's in the nursing home include the nurse practitioner (NP), gerontological nurse practitioner, the Clinical Nurse Specialist (CNS), and the gerontology certified CNS. These clinicians are typically masters or doctoral prepared nurses with advanced practice clinical skills in the areas of health assessment, chronic disease management, health promotion, and health maintenance, who provide holistic health care to nursing home residents. Gerontological nursing is the field they have chosen, which means they are prepared to provide and manage the health care needs of older adults, including medical treatment, rehabilitation, and end-of-life care, as well as to serve as health care educator to residents, families, and nursing home staff, and to

take the role of resident advocate and gerontological research consumer (St. Pierre & Conley, 2010). The APRN in this setting collaborates with other health care professionals to manage the health care and quality of life needs of nursing home residents.

Medical health care providers in long term care are few and far between. There are currently over 15,000 nursing home facilities in the U.S (American Health Care Association (AHCA), 2012) serving almost 1.5 million residents and an additional 1 million residents in assisted living facilities (National Center for Assisted Living, 2011) with less than 5000 geriatricians and 7500 gerontological APRNs available to provide them with specialized medical care (American Nurses Association, 2011; National Gerontological Nurses Association, 2012). Geriatrics/gerontology is not a popular field for medical care providers. Only 22.6% of active physicians report spending some time in nursing homes, and those who do have nursing home practices, report spending only 2 hours per week or approximately 4% of their work time actually in nursing homes (Katz, Karuza, Kolassa, & Hutson, 1997).

Similarly, only 3% of nurse practitioners and a similar percentage of clinical nurse specialists report employment in nursing homes (US Department of Health and Human Services, 2010). However, the findings of a review of the literature on the care of nursing home residents by APRNs suggests that these nurses spend a majority of their practice time in the long term care setting and that increased APRN time spent in these settings has a positive impact on quality of care and patient satisfaction (Bakerjian, 2008). APRNs currently practice in various levels of collaboration with physicians in nursing homes. Depending upon the APRN scope of practice mandated by individual state laws, these nurses may collaborate on a daily basis with the “supervising” physician or on a less frequent “as needed” basis.

A meta-analysis of studies that compared NP care to physician care in the areas of assessment, health promotion, and treatment of chronic conditions found that NP care was equivalent to, and at times, better than, care provided by a physician (Brown & Grimes, 1995). APRNs have been found to improve care in nursing homes, including lowering rates of hospitalizations and emergency room visits (Burl, Bonner & Rao, 1994; Garrard et al., 1990; Intrator, Zinn, & Mor, 2004; Joseph & Boult, 1998), as well as increasing resident autonomy, preserving resident dignity, and overall, providing more holistic, resident-centered care (Abdallah, 2005; Kappas-Larson, 2008). Thus because APRNs increase the numbers of medical care practitioners in nursing homes with their presence and through their collaboration with physicians, and because they are educated as nurses to provide holistic care, they appear to be in an ideal position to improve person-centered medical care in this setting. Given the great need for qualified, effective, resident-centered health care in this setting, it seems the gerontological APRN can and should play a large and important role in the health and quality of life of future nursing home residents. The secondary analysis in this work describes nursing home stakeholders' perceptions of how APRNs may make a difference in involving residents in their chronic illness care.

Statement of the problem

Much of the research literature surrounding person-centered care in the nursing home is focused on providing choices regarding activities such as meal, bath, and sleep routines (Crandall et al., 2007; Luff, Ellmers, Eyers, Young, & Arber, 2011). Choices regarding chronic illness management can greatly affect an individual's daily activities and quality of life, yet there have been few studies examining nursing home residents' opportunities for involvement in their daily plans of health care and perceptions toward

their involvement. It is tempting to assume, because of increasing frailty or cognitive decline, that many nursing home residents are uninterested in their daily health care routines or that they are ready to be cared for in whatever way others feel is best for them. However, studies have shown that some residents have a desire for and are capable of making decisions about their care and being involved in their care (McCabe, Hertzog, Grasser & Walker, 2005; McNabney, Wolff, Semanick, Kasper, & Boult, 2007).

Nursing homes stressed by health care provider shortages and decreasing financial resources may not be prepared to provide the autonomy and person-centered care expected by the Baby-boom generation. Given the increasing number of older aged people with chronic illnesses predicted to be entering nursing homes in the coming years (Healthcare Intelligence Network, 2006) and the probability that the aging "Baby boom" generation will expect to retain more autonomy over all aspects of their lives for as long as possible (AHA & FCG, 2007), there is an urgent need for research evidence to inform the systematic implementation of person-centered chronic illness care in the nursing home. A first step to accomplish this is to describe current chronic illness management practices in the nursing home setting focused on the involvement of older-aged nursing home residents in decision-making and self-care activities within their plans of care and to explore how that involvement may be enhanced.

Research aims and questions

Aim 1: Describe the quantitative literature surrounding chronic illness management in the nursing home setting using type 2 diabetes as an exemplar.

Research Question 1: What are the current type 2 diabetes management practices in the nursing home setting?

Aim 2: Describe the qualitative literature surrounding involvement of older-aged chronically ill persons in everyday decisions regarding their chronic illness plans of care.

Research Question 2.1: What does involvement in daily chronic illness medical care decision-making mean to older-aged people (in the community and in nursing homes)?

Research Question 2.2: What factors do older-aged people perceive improve or hinder their involvement?

Aim 3: Describe the opportunities for nursing home residents to be involved in their chronic illness management decisions and in active self-care of their chronic illnesses and describe how the APRN medical care provider can enhance that involvement as perceived by key stakeholders in the nursing home setting.

Research Questions 3.1: What are the perceptions of key stakeholders in the nursing home setting including residents, family members of nursing home residents, advanced practice nurses, physicians, and nursing home administrators regarding:

Research Question 3.1.a: The opportunities for nursing home residents to be involved in making decisions regarding their chronic illness plans of care?

Research Question 3.1.b: The opportunities for residents to be actively involved in self-care activities within their chronic illness health regimens?

Research Question 3.1.c: The qualities that APRNs possess or need to possess to enhance residents' involvement in decision-making and self-care activities within their chronic illness plans of care?

Aim 1 was addressed by the first project in this dissertation, the systematic review of the literature focused on type 2 diabetes management in the nursing home, found in Chapter 2 of this work. Aim 2 was addressed by the qualitative review of literature surrounding chronic illness decision-making by older adults in the community and in nursing homes, presented in Chapter 3. The third project of this dissertation, the ethnographic pilot study in the nursing home, addressed both Aims 2 and 3. Aim 3 was directly addressed by the qualitative descriptive secondary analysis study of nursing home stakeholder perceptions regarding opportunities for residents to be involved in their chronic illness plans of care and self-care activities and their perceptions as to how APRNs can enhance that involvement. The justification for this study is described later in this chapter and the findings are detailed within the manuscript presented in Chapter 4.

Definitions

1. *Chronic illness care*: Comprehensive, individualized health care aimed at maintaining the highest state of health possible through a proactive health care team focused on empowerment and education of residents to self-manage, prevent symptoms, and maintain ongoing communication with health care professionals (Wagner, Austin, Davis, Hindmarsh, Schaefer, & Bonomi, 2001).
2. *Person-centered care*: Health care provided in an environment of respect and dignity for the individual, where the preferences, concerns, and self-expressed needs, wants, and values of the well-informed person guide all clinical decisions (Berwick, 2009; IOM, 2001).
3. *Decision-making involvement*: Informed and valued participation by a resident in choosing and determining daily health regimens that address the chronic

illnesses and disabilities he/she faces. An example would be when a health care provider explains the actions and side effects of several pain medications to a resident and/or family, allows time for questions and comments, provides his/her recommendation, and then asks the resident his/her preference, and allows the resident to choose the type of pain medication to be administered. Effort by the health care provider to abide by the resident's informed preferences helps to communicate to them the high value placed on their participation.

4. *Active self-care involvement*: Informed and valued participation by a resident in self-care or self-management activities to treat and prevent symptoms regarding chronic illness and health care maintenance plans. An example would be providing information regarding purpose of, use of, and availability of blood glucose monitors and, if desired by the resident, assisting him/her to check and document his/her own blood glucose levels, at times agreed upon by the resident and facility.
5. *Long term care*: A service provided by professional caregivers to people who need and seek personal and professional assistance to continue their lives as close to their normal routine as possible.
6. *Nursing home*: A type of long term care facility that provides a comfortable and safe, place to live with immediate access to personal, daily living assistance and to professional medical attention, as needed and desired by the resident, where the resident's legal and civil rights are protected (IOM, 1986).
7. *Quality of life*: A state of being in the world that lies on a continuum between happiness, satisfaction, and comfort to misery, frustration, and pain.

8. *Advanced practice registered nurse*: In the nursing home setting, refers to registered nurses who are certified as either nurse practitioners or clinical nurse specialists, and who have the education, experience, skills, and mind set to manage acute and chronic physical and mental problems, as well as to teach, counsel, support, and advocate for patients and peers (Bakerjian, 2008).
9. *Advanced practice registered nurse qualities*: Characteristics, values, goals, insights, and skills possessed by a nurse who has chosen to care for and meet the medical, functional, psychological, and social needs of the nursing home resident. Examples of these qualities might include: compassionate communication skills, time commitment to the gerontological nursing home patient; and the ability to coordinate and manage care within federal, state, and facility regulatory guidelines.

Assumptions

The assumptions underlying this dissertation research study are:

1. Providing person-centered care to all residents, regardless of degree of cognitive impairment, is a primary aim for all nursing homes in order to promote the highest quality of life and quality of care.
2. Nursing homes are generally under-resourced, minimally staffed, and thus, greatly challenged to provide a person-centered philosophy and environment.
3. Providing multiple perspectives of opportunities for residents to be involved in their chronic illness decisions and self-care activities from the major stakeholders involved in these decisions and activities allows for a more balanced, complete, and cohesive description of their involvement.

4. The residents in this study did not have major cognitive impairment and thus were capable of making their needs and preferences known.
5. If encouraged, the majority of cognitively unimpaired and mildly impaired persons in nursing homes are capable of making their needs and preferences known regarding their daily health care plans and activities.
6. Nursing home residents desire different degrees of involvement in chronic illness care planning and self-management.
7. Nursing home residents' perceptions and preferences regarding health care are influenced by their individual and group cultures and backgrounds as well as by the culture of the nursing home environment.
8. Improvement of resident involvement in health care decision-making and self-care activities to the extent desired by the cognitively capable resident will increase the quality of resident-centered care so that the resultant quality of life and health outcomes are congruent with the resident's preferences.

Sensitizing framework

Use of a sensitizing framework in qualitative research

Qualitative research is undertaken to describe a rare or unusual phenomenon about which little is known or when the researcher feels existing knowledge is incomplete (Morse & Field, 1995). The qualitative descriptive method provides an accurate accounting of a phenomenon or event and an emic but minimally interpretive description of the meaning of that event to the participants (Sandelowski, 2000). The secondary analysis study in this dissertation research uses the qualitative descriptive method to understand and describe the phenomenon of nursing home resident opportunities for involvement in chronic illness decisions and self-care activities, which

is not well-defined in the literature, especially from the joint perspectives of the resident and other major stakeholders in this setting.

The researcher used a sensitizing framework for chronic illness care, the Chronic Care Model (Wagner, 1998), as a context from which to guide or frame the research questions and the secondary analysis. (Permission to use the model was provided by The American Academy of Physicians; see Appendix A.) The framework provided a lens through which to view the data from a different perspective than used in the parent study. The Chronic Care Model (CCM) is a very broad conceptual framework with applications in all types of health care settings. The researcher chose to view this data through this model because it is, in a sense, a grand theory, that will serve as the guide for this researcher's overall plan of work in person-centered care in the nursing home setting. Thus, the concepts of the model served as an abstract, underlying background that connected the problem, the questions, the analysis, and the findings. The model did not restrict the findings, but rather provided a rich environment in which to nest new knowledge regarding resident involvement in chronic illness care. The information gleaned from this study informed refinement of the CCM adapted to the nursing home setting by this researcher.

The Chronic Care Model

Dr. Edward Wagner is an internist/epidemiologist, professor, and director of the W.A. MacColl Institute for Healthcare Innovation and the creator of the CCM. His vision was to provide a guideline for others to follow when planning effective care for the chronically ill (Improving Chronic Illness Care (ICIC), 2012; Wagner, 1998). The CCM is based on the principle that care of the chronically ill occurs in three primary domains: the community and its resources, the healthcare system and its resources, and the health

care provider system (Bodenheimer, Wagner, & Grumbach, 2002). The primary goal of the model is to have constant intercommunication among these elements. Ideally, the patient is informed and active in self-care and the health care team is appropriately educated and organized in a way that optimizes patient outcomes. This model has been successfully used to improve outcomes in many healthcare practice settings (Bodenheimer et al., 2002; Bodenheimer, Wagner & Grumbach, Part 2, 2002; ICIC, 2012). The CCM is not meant to be an explanatory theory, but rather, a flexible evidence-based guideline in providing person-centered chronic illness care, subject to change as new evidence emerges (Wagner et al., 2001).

CCM model elements and significance to the nursing home setting.

Health systems. The MacColl Institute describes the Health System as an organization with a unique culture and with mechanisms in place to promote safe, high quality care (ICIC, 2012). The nursing home system is led by the administrator, who generally works under the authorization of the facility owners. Both owners and administrators must consider their own philosophy of care, federal and state rules and regulations on long-term care, and financial limitations when cultivating a nursing home organization plan. The administrator and owners of the nursing home are the initiators of high quality care. Their actions and the manner in which they convey the importance of communication and resident-centeredness determine whether quality, chronic illness care will take place.

Delivery system design. This element stresses increasing the involvement of and collaboration with non-physician members of the team and shifting provider-patient visits from being reactive (to an ongoing symptom or new symptoms) to proactive (focus on health promotion and prevention of symptoms) (ICIC, 2012). In the nursing home system, this concept primarily relates to the type of medical model or delivery of primary

medical care chosen by the system owners and administrators. This element is extremely important to the delivery of person-centered care and was the primary focus of the parent study. It will not, therefore, be focused upon in this current work.

Self-management support. Per the CCM, the Self-Management Support element is about empowerment of patients. It is an essential, if not the quintessential part of the delivery of person-centered chronic illness care. It means that the health care provider and the entire health care system must acknowledge and support that the patient is the director of his/her own care, quite different from traditional medical care. In addition, the system as a whole must provide ongoing, systematic support, education, and proven strategies to encourage the patient to seek information, set goals, create treatment plans, and solve problems (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997).

The nursing home system is no different in this regard than any other health care system. Regardless of age or residential status, all people who are cognitively capable of making informed choices engage in behaviors and make decisions that impact their health, otherwise known as self-management (ICIC, 2012). In the nursing home these choices may include: dietary habits, medication requests, treatment regimens, exercise habits, sleep habits, hygiene, personal appearance maintenance, mental health activities, leisure time activities, and social network maintenance. The CCM maintains that control of chronic illness and its outcomes depends to a significant degree on self-management or self-determination of healthy behaviors.

Decision support. The CCM describes the Decision Support element as ensuring that providers incorporate evidence-based guidelines into daily plans of care and that they provide patients with the information needed to understand the principles behind medical recommendations. This helps patients feel comfortable voicing their preferences and opinions regarding medical care plans. Care of chronic conditions in older aged persons

often entails specialized clinical practice guidelines set forth by teams of medical experts, such as the *American Medical Directors Association's Diabetes Management in the Long-Term Care Setting Clinical Practice Guidelines* (2008), discussed in detail in Chapter 2 of this work. These specialized guidelines for older adults may differ substantially from those recommended for healthy younger adults, emphasizing the importance of gerontological expertise in nursing home health care providers. A major challenge in implementing care guidelines for nursing home residents is balancing the person's advanced age with the rigidity of the health targets that generally have been set for younger individuals. Providing adequate information to capable and interested nursing home residents about their chronic illnesses, including any specialized practice guidelines and their implications, is imperative if they are to feel comfortable in making decisions regarding their chronic illness health care regimens.

Clinical information systems. This element centers on electronic information systems to assist providers in implementing, team-oriented, patient-centered care. This element is not a focus of this dissertation work.

The community. Surrounding the Health Care System element of the CCM is the Community element. The CCM views the community in which the health care system is located as the people, organizations, and governing bodies that advocate for, contribute to, monitor, and enforce the policies and regulations by which health care systems must abide. A nursing home system is heavily regulated, possibly more heavily regulated than any other health care system, as a result of concerns regarding quality of care, abuse, and neglect. This element is not a focus in this current work.

Resident (and family), Practice Team, and Productive Interactions. The Productive Interactions between patients and the health care team can only take place if the resident (and family) are informed and activated. In the model, being "informed,"

refers to a patient (or resident) having enough information about illness and treatment options to take part in self-care and decision-making, intelligently and comfortably. When a patient is "activated" he/she is aware of the importance of his/her role in the care of chronic illness and knows that his/her input is highly valued. These characteristics can only manifest if the health care system is doing all of the above actions.

In the nursing home setting, resident-centered communication or productive interactions between providers and residents is the result of a proactive team of health care professionals working with and within community resources and policies to place the nursing home resident at the center of his/her chronic illness care. All the elements of the model must act and interact to produce outcomes that reflect the resident's preferences.

Outcomes. Outcomes of the CCM include effects on patient health and quality of life, often measured by number of hospitalizations, resident satisfaction, and cost analyses. In the nursing home setting and in the context of patient-centered care, outcomes may be more appropriately labeled as health and quality of life congruent with resident preferences. The measurement of outcomes was not a focus of this work. Rather, this work focused on describing the elements of decision support, management support, and productive interactions between the practice team and the resident/family that may influence nursing home resident involvement opportunities in chronic illness decisions and self-care as described in the literature and from the perspectives of nursing home stakeholders.

Use of the CCM in this study. The Community (including regulations and policies), Delivery System Design, Clinical Information Systems, and Outcomes are significant elements in the model, but were not a focus of this dissertation study. These elements will be addressed in future studies. The elements of the CCM that were used in

this research include the Health Care System, which includes the system's leader, the nursing home administrator; the Practice Team, led by the physician and APRN; the Patient, or nursing home resident and the resident's family member; Productive Interactions, or the quality of communication between providers and residents/family; Decision Support, including sharing of expert information with residents so they are comfortable with self-determination and self-management of their chronic illnesses; and Self-Management Support, the acceptance of the resident as the director of his/her own health care management and the provision of ongoing, systematic education and support of the resident encouraging active participation in chronic illness decision-making and self-care.

Research Question 1 was primarily informed by the Decision support element of the model focused on clinical practice guidelines. Questions 2 and 3 were informed by the Decision Support, Management Support, Productive Interactions, APRN, Physician, Activated Resident (and Family), and Administrator (Health Care System) elements of the model.

The pilot study

Description of the study

A pilot study was conducted by this researcher and her faculty sponsor, Dr. Tracie C. Harrison, to determine the feasibility of an ethnographic design to explore nursing home residents' perceptions and preferences for chronic illness care, using type 2 diabetes as an exemplar illness. Diabetes was chosen as an exemplar because its prevalence in nursing homes is increasing, evidenced by a 62.4% increase from 1994 to 2004 (Sloan, Bethel, Ruiz, Shea, & Feinglos, 2008); a continued increase by 18.5% over the last six years; and a current prevalence of 33.3% as of the third quarter of 2010

(CMS, 2010). The many opportunities for resident decision-making and active involvement in self-care activities available in the management of type 2 diabetes also made it an ideal exemplar chronic illness to study the phenomenon of nursing home resident involvement in chronic illness decisions and self-care activities.

Background

The American Medical Directors Association (AMDA, 2008) mandated individualized diabetes care in nursing homes as a primary component of a systematic approach to treatment. In older adults with limited life expectancy and multiple physical and cognitive impairments, glycemic goals may be relaxed or individualized (American Diabetes Association, 2010). Individualized care "must take into account the patient's cognitive and functional status, severity of disease, coexisting conditions, expressed preferences and life expectancy" (AMDA, 2008, p. 4). Determining the degree of glycemic control can be a complex, and often controversial, decision for nursing home practitioners, facilities, residents, and their families due to the many factors to be considered. One of the most important of these factors is the preferences of the resident, which were explored in this pilot. The conceptual framework for the study was Kleinman's (1980) explanatory models. The primary research question was: *What is the explanatory model that describes the treatment experiences (perceptions and preferences) of nursing home residents living with diabetes?*

Methodology

Approval was obtained from The University of Texas at Austin Institutional Review Board and the study was undertaken in one central Texas nursing home. Through purposive sampling, 3 nursing home residents, 2 females and 1 male, with a mean age of 78.7 years were sampled over a three-month period. Only residents capable of providing

independent informed consent were sampled and consent was obtained from the nursing home administrator prior to initiating recruitment. One audiotaped interview and two observational visits were conducted per participant. Field notes were recorded and medical records were used to obtain demographic data. Domain analysis, explanatory modeling, and descriptive statistics were used to analyze the data. Data analysis was ongoing throughout the interview process with revision of interview questions as the data suggested. Trustworthiness was obtained through an audit trail documenting all facets of the study including a table documenting the phases of analytical decision-making. The rigor of the study was strengthened by review of method and analyses by the researcher's faculty sponsor, an expert in qualitative research and aging with disability.

Data analysis

Domain analysis methods were used to analyze the data and involved organizing the interview data into domains using symbols, referents, and semantic relationships as described by Spradley (1979). The interviews were transcribed and the typed transcripts were compared to the tapes for accuracy. Domain analysis involved a preliminary identification of domains based on disease concepts: cause, severity, treatment, and goals, followed by line-by-line coding of key phrases and passages in the text, reading and re-reading the texts to determine how the key phrases should be grouped into subcategories and later into primary domains. These domains and subcategories were then analyzed using the participant's actual words to determine relationships between sub-categories and finally between the domains. The sub-categories, domains, and relationship statements gave rise to a rudimentary development of an explanatory model for the participants.

Results

Two themes of resident perceptions of having diabetes were: *Too many shots* and *No choice*. Residents expressed discontent over the many needle sticks they received in the course of a day including multiple insulin injections and multiple finger sticks for glucose monitoring purposes: “You run out of fingers.” They perceived they had few choices in treatment options within this setting: “have to learn to live with it” and “I’m stuck here.” Themes regarding resident preferences for diabetes treatment included: *Fewer sticks* and *More knowledge through better communication*. Although they felt they had little choice in the number or timing of their needle sticks, they expressed that if it were possible they would “like to get rid of the sticking.” Residents also described problems with lack of knowledge regarding diabetes treatment choices, which they attributed to too few visits from their practitioners and lack of meaningful communication with them: “she’s [the practitioner] a phantom you know” and “I was trying to learn but everything’s a big secret.”

Conclusions

People with type 2 diabetes in the community setting, providing their own self-care, make choices daily, such as how often to check their blood glucose levels. Nursing home residents have the right to refuse treatment or request individualized treatment as long as they are able to clearly understand the risks and benefits of the treatment plan. Despite these rights, the perceptions of this small sample were that they did not have the knowledge, power, or option to influence their type 2 diabetes management regimens. These findings contributed to the research questions addressed in the final project of this work, which included describing the opportunities available for nursing home residents to participate in their chronic illness care regimens and decision-making and how these opportunities may be improved.

Considerable effort was necessary to attain access to this vulnerable population but once approved, the methods proceeded as designed. Lessons learned from the pilot study were that although the proposed design was feasible, limiting the sample to only those with diabetes possibly led to slower recruitment. Additional audiotaped interviews and observations and the ability to interview and observe other members of the nursing home culture would add to the ability to provide a more in-depth perspective of this phenomenon. Although, this ethnographic method proved feasible, the researcher was provided access to qualitative data collected for a similar study, which allowed the exploration of the same phenomenon of interest regarding chronic illness in general. Because the area of resident involvement in chronic illness plans of care is relatively new and unexplored from an emic perspective, a qualitative descriptive approach was chosen for the dissertation research.

Summary

Care of elderly persons in nursing homes is an immense responsibility given the general vulnerability and often frail state of the resident population. With the continuing increase in the older-aged population, especially those 80 and above and those of diverse ethnicities, combined with the parallel increase of chronic illness and the entrance of a generation that may be more demanding of health care information and autonomy, this responsibility only grows. A pilot ethnographic study was conducted in a nursing home to test feasibility of methods. Once access to residents in the nursing home was approved, methods proceeded smoothly, and residents voiced definite preferences for diabetes care.

Because the researcher was given the opportunity to access qualitative data that had been recently collected for a similar study, she was able to explore nursing home resident involvement in chronic illness care not only from the resident's perspective but

also from the perspectives of other stakeholders in this unique health care setting. Due to the lack of scientific literature in this area, qualitative description was chosen as the approach for the final project of the dissertation research. Thus, a secondary analysis of qualitative data was conducted to provide clear and informational descriptions of resident involvement in chronic illness care as well as new insights into this phenomenon through the combined perspectives of major stakeholders in this setting. It was hoped that this study would inform a more in-depth ethnographic study in the future.

THE SECONDARY ANALYSIS STUDY

The final project of this dissertation work was a qualitative descriptive study of secondary data from research conducted in the nursing home setting by Harrison and colleagues in 2012. A justification for the secondary analysis and a detailed description of the procedures used to conduct this study are presented below.

Justification for the secondary analysis

Secondary analysis is defined as the use of a data set collected for purposes of a previous study to investigate an alternative research question or area of interest, separate and distinct from that of the prior and original work (Hinds, Vogel, & Clark-Steffen, 1997). This type of inquiry is commonly undertaken and accepted as having great value in quantitative research. It is less common in qualitative research, but its acceptability and contribution to the literature is growing (Heaton, 1998). This acceptability is largely due to the ability of this form of research to continue to generate new knowledge from data collected from participants who may be difficult to access due to vulnerability or rarity (Thorne, 1998; Sandelowski, 1997; Szabo & Strang, 1997).

Secondary qualitative analysis has also been found to be cost-effective and time-efficient (Estabrooks & Romyn, 1995; Heaton, 1998), important issues in today's

economic environment of decreasing funds for research and increasing demands on both researchers and participants. Decreased burden on participants, who in health care research, are often stressed by physical, emotional, and social problems is also a very strong consideration when choosing to conduct a secondary analysis of qualitative data (Estabrooks & Romyn, 1995; Szabo & Strang, 1997).

Compatibility of the data

For the final study of this dissertation, secondary analysis was appropriate for several reasons. The first question generally asked of a secondary analysis of qualitative data is whether the data are compatible or fit the new research questions and method (Thorne, 1998). This analysis used the same method, qualitative description and content analysis, used in the parent study but asked different questions of the data and used a different theoretical framework through which to view the data. The parent study focused on resident and family choices regarding the selection of a primary medical care provider in the nursing home setting and used an organizational framework to study the quality and efficiency of primary medical care service delivery models in nursing homes. The secondary analysis used an adaptation of the CCM to frame the analysis of the data. Additionally, the perceptions of stakeholders regarding APRN qualities that may influence resident involvement were also described.

The primary reason why these data were compatible with the secondary analysis questions was that both studies were focused on stakeholders' perceptions of medical management choices provided to the resident. One of these choices was the selection of a medical care provider, which was the primary focus of the parent study. However, other choices were explored such as medication regimen choices and diet and exercise routines. The PI of the parent study allowed this researcher to add a few specific questions to the

interview questionnaire, which were slightly more directed toward resident involvement in these types of decisions and in self-care activities. The data from these particular questions and from the overall interviews focused on residents' health care choices provided rich data for the secondary analyses research questions.

Another reason why this data was compatible with the secondary analysis research questions was the uniqueness of the stakeholders' perspectives as a whole. These multiple perspectives added to the depth and dimension of the description of resident involvement in this setting and APRN qualities that may influence that involvement. Thus, like methodologies, different but related research questions, and different theoretical framing of the design and analyses, made these data compatible for the secondary analysis to not only generate new knowledge but to complement the findings of the original study.

Access to the data

Next, secondary analyses must address access to the data, knowledge of the parent study, and access and coordination with the parent study's lead investigator (Szabo & Strang, 1997). The secondary analyst, this researcher, was a graduate research assistant on the original work and assisted with Institutional Review Board approval efforts, recruitment, and data collection. A difficulty often encountered in secondary qualitative analyses is the loss of dimension of interpretation and understanding due to not being present during the interview with the participant or not having complete access to all interview data. This researcher was present as interviewer or observer in many of the participant interviews. De-identified verbatim transcripts of all interviews, de-identified demographic data to provide context to the data, and access to the principal investigator

of the parent study were readily available to this researcher and added to the quality and depth of the secondary analysis.

A further advantage was that the principal investigator of the parent study is a renowned qualitative researcher, instructor, and mentor to this researcher. She was available and open for questions regarding methodology and validation of connections made in the data to ensure they fit or resonated with the parent data source, which also contributed to the trustworthiness of the data (Szabo & Strang, 1997).

Ethical considerations

Ethical concerns with secondary data analyses include questions regarding informed consent. Heaton (1998) stresses the importance of obtaining consent, which covers the possibility of secondary analysis as well as the current research whenever primary research is undertaken. The consent forms approved by The University of Texas at Austin IRB and used in the parent study explicitly stated that the data may be used for future, related studies and stressed that participants' confidentiality would be protected.

Need to describe the parent study

Finally, it was imperative that the parent study design, methods, and data collection procedures were reported in detail as well as the data analysis procedures for the secondary analysis, including descriptions of the processes undertaken to categorize and summarize the data (Thorne, 1994). Chapter 4 presents the methods and findings of the secondary analysis and provides a description of the design and methods used in the parent study. A detailed description of the methods used for the secondary analysis follow below, including specific procedures undertaken to ensure trustworthiness of the findings.

Design and methodology

Design

Qualitative description is a methodology within the epistemology of constructionism. In constructionism, meaning is only perceived when the mind interacts with an object, thus "all reality, as meaningful reality, is socially constructed" (Crotty, 1998, p. 54). Meaning is built from how people interpret their interactions with each other. Qualitative description allows a blend of descriptive methods to yield foundational knowledge and of interpretive methods to facilitate the emergence of underlying meaning from the data. In qualitative description, the goal is to relate a vivid description of all aspects of the phenomenon or experience while staying close to the surface of the data (Milne & Oberle, 2005). Using a qualitative descriptive method, this study was able to richly describe nursing home stakeholders' views and preferences regarding their involvement in chronic illness health care decisions and self-care activities. Additionally, this method allowed the use of a conceptual framework through which to view the data, which allowed further description of how stakeholders' perceptions and preferences influenced the provision of patient-centered chronic illness care.

Methodology

Demographic data. De-identified demographic data collected by the parent study researchers and entered into SPSS version 20 was provided to this researcher by the PI of the parent study. It was used to describe the sample and added context to the qualitative data.

Qualitative data. De-identified qualitative data, transcripts of the qualitative interviews conducted with each participant by the parent study researchers, were provided to this researcher by the PI of the parent study. Qualitative content analysis

(QCA) was used to analyze the data. QCA is a method of describing data that is systematic, flexible, and focused or summative (Schreier, 2012). It is systematic in that it requires all data to be subjected to the same pattern or sequence of analytical processes, which provides for the consistency and reliability of the method. This sequence of analytical processes or steps used in the analysis can be loosely framed from a conceptual theory but this framework must remain adaptable and open to fit the focus of the research questions, the actual words of the participants, and any new concepts, themes, or directions emerging from the data (Zhang & Wildemuth, 2009). These new themes may validate or extend the framework (Hsieh & Shannon, 2005). Looking at the data through the lens of a theoretical model allows the data to be viewed on a more abstract level, allowing new information in the data as a whole to emerge. QCA is a method of categorically describing data that allows emic interpretation of participants' words based on a systematic process of both deductive and inductive coding, categorization, and thematic recognition (Hsieh & Shannon, 2005).

Immersion in the data. The secondary analysis began by systematically reading and re-reading the transcripts noting any impressions in analytic field notes to immerse the researcher in the data. Immersion of the researcher in the data facilitated the ability to view the data more abstractly, and thus allowed the emergence of themes or unifying threads between concepts to be recognized (Zhang & Wildemuth, 2009). Analytic field notes were recorded in the form of an analytic journal, noting the overall tone or mood of the interview and any striking impressions. These memos were used to help find patterns in the data (Szabo & Strang, 1997). Transcripts were read through at least twice prior to coding to obtain a sense of the interview as a whole (Tesch, 1990).

Coding and categorizing. QCA techniques recommended by Margrit Schreier (2012), a professor of qualitative and quantitative research methods in the social sciences,

were used to conduct the analysis. This guide was chosen because it clearly described how both deductive analyses using a theoretical framework and inductive analyses using collected data could be integrated to generate categories and subcategories in QCA that produce an emic description of a phenomenon viewed through the lens of a conceptual framework. The first step in QCA is devising a coding frame (Schreier, Ch. 4). Key aspects of each research question were chosen; these became the foci of the analysis. These foci, also termed dimensions or categories, were largely decided upon by the researcher based on the research questions and generally on what the researcher was interested in describing or finding out (Schreier, Ch. 4). Subcategories were then named that specified what was said in the data about each category. Subcategories were derived deductively from a conceptual framework and/or inductively from what was in the data (Schreier, Ch. 5). Most QCA studies use a combination of deductive and inductive methods to derive the coding frame to ensure that no data are disregarded and because the method inherently has already specified some relevant dimensions in the research questions and interview guide (Schreier, p. 106)

Initial categories and sub-categories consisted of an integration of elements or concepts from the CCM, the research questions, and the interview questions. Categories were renamed using participants' words and new categories were added during coding with the intent of developing a coding scheme that stayed close to the surface of the data (Sandelowski, 2000) but allowed for the emergence of additional categories as the data dictated within each question. Coding frames generally have at least two levels but may have more depending on the complexity of the topic and the depth of description that the researcher wishes to convey. Each category and subcategory was defined as to what fit in that category and what did not – this was more important in sub-categories as they

generally defined the categories (Schreier, Ch. 5). Once the coding frame was in place and defined, segmentation of the data began.

Segmentation of the data involved dividing the data, line by line, into units of coding based upon topics covered by a segment of text, i.e. as a portion of text changed topic, a new segment of data was marked (Schreier, 2012, Ch. 7). Once segmentation of each unit of analysis (or interview) had been accomplished, coding of individual segments began. These segments were numbered according to subcategory. This was done on a second copy of the segmented data or separate document so that the researcher could return to the segmented un-coded data and re-code at a later time to check for coding consistency (Schreier, Ch. 7).

During coding, more categories and subcategories were added to the coding frame, category names were changed to reflect the participants' words, and subcategories were collapsed into larger categories, inductively building a modified framework from which to code the rest of the data (Saldana, 2009; Mayring, 2000; Morse & Field, 1995). Analytic memos were kept on the data worksheet and the analytic journal to record researcher reflections, initial interpretations, and reasoning as to why certain codes or categories were named as they were; these notes assisted the researcher to analyze the codes and categories and helped to illuminate subcategories and major categories (Saldana, 2009). Exemplars for each category and code were identified from the data to assist in reporting the findings and to ensure the analysis had remained close to the words of the participants (Morse & Field, 1995).

Below are the research questions addressed by the secondary analysis followed by a description of the processes used to answer the questions and the categories used to analyze the data. The categories for each question were derived from the concepts of the CCM model that were thought to most pertain to the question.

Research Question 3.1.a. : *What are the perceptions of key stakeholders in the nursing home setting including residents, family members of nursing home residents, advanced practice nurses, physicians, and nursing home administrators regarding the opportunities for nursing home residents to be involved in making decisions regarding their chronic illness plans of care?*

This question was answered by employing the above described processes including: immersion in the data; recording of impressions and analytic decisions in analytic memos; segmentation of the data; and line by line coding. The key concepts of interest or major categories within this question were derived from the CCM concepts of Self-management support (information and importance), Decision support (willingness and comfort), and the interview questions which asked participants to describe if they thought residents wanted to be included in chronic illness decisions and to describe what gave them that impression (expectations and characteristics) included:

- Available chronic illness care choices, such as diet or meal planning, daily exercise regimen, choice of medication type, or timing of treatments;
- Opportunities to obtain/provide chronic illness information, such as provider visits and care plan meetings;
- Opportunities to promote decision-making activation (where resident is aware of the importance of their role in decision-making), such as resident council meetings or active listening;
- Indicators of willingness, both of resident willingness to be involved and of provider willingness to involve the resident;
- Indicators of comfort level, both of resident to feel comfortable expressing preferences and provider to feel comfortable in accepting preferences;

- Perceptions of resident characteristics that impact decisional involvement, characteristics such as cognitive ability or level of education that impact a resident's ability or desire to be involved in decision-making; and
- Perceptions of expectations, whether resident expects or is expected to be involved in decision-making.

Further categories and subcategories were developed throughout the analysis as the data dictated. Demographics for participants were used to provide context for the descriptions. Quotes from participants were used to add depth and richness to the descriptions and to aid the reader in understanding these perceptions as seen through the eyes of this stakeholder group.

Research Question 3.1.b. : *What are the perceptions of key stakeholders in the nursing home setting including residents, family members of nursing home residents, advanced practice nurses, physicians, and nursing home administrators regarding the opportunities for residents to be actively involved in self-care activities within their chronic illness health regimens?*

As above, this question was analyzed using the same processes as described for QCA. The categories for this question were very similar to the above question and included:

- Available chronic illness care activities, such as meal preparation, blood glucose testing, or self-use of exercise equipment;
- Opportunities to provide/obtain chronic illness self-care information, such as expert consults or educational meetings;
- Opportunities to provide self-care support, such as providing access to exercise equipment or reminders to self-medicate;

- Indicators of willingness, both of resident willingness to participate and of provider willingness to encourage participation;
- Indicators of comfort level, both of resident to feel comfortable participating and of provider comfort in encouraging participation;
- Perceptions of resident characteristics or abilities that impact active participation, whether resident's functional/physical ability or cognitive status impacts ability or desire to participate in self-care activities; and
- Perceptions of expectations, whether resident expects or is expected to be involved in self-care activities.

Demographics and quotes from each participant were used to add context and richness to the descriptions.

Research Question 3.1.c. : *What are the perceptions of key stakeholders in the nursing home setting including residents, family members of nursing home residents, advanced practice nurses, physicians, and nursing home administrators regarding the qualities that APRN's possess or need to possess to enhance residents' involvement in decision-making and self-care activities within their chronic illness plans of care?*

QCA methods were used including immersion in the data, segmentation of the data, line by line coding, and categorizing. Initial categories for this question were derived from the CCM concept of Prepared provider (APRN) (education and skills) and the interview questions that asked what qualities the ideal health care provider needed to possess and what qualities an APRN in this setting needed to possess (goals and personal traits) included:

- Education, including degrees obtained, nursing experience, and gerontology experience;

- Skills, such as clinical, communication, and teaching expertise;
- Goals, including goals for residents as well as personal and professional goals; and
- Personal traits, such as patience and compassion.

Some category names were changed to make them closer to the participants' words, and quotes from the interviews were used to provide a more detailed description that vividly conveyed the stakeholders' point of view.

Anticipated results

It was anticipated that the end product of the analysis would be an emic description of residents' involvement in chronic illness care decision-making and active self-care, as well as APRN qualities enhancing that involvement, within the nursing home setting. Additionally, it was hoped that results would inform the following concepts and relationships in the adapted CCM: the Health Care System, Decision Support, Self-Management Support, Practice Team, Patient/Family, and Productive Interactions. It was not expected that results would inform the CCM elements of: Community, Health Care Delivery Systems, Clinical Information Systems, and Outcomes (such as number of hospitalizations or patient/provider satisfaction). Exploration of these model elements was reserved for future studies.

Data management

All data obtained from the parent study had been previously de-identified and was referred to only by the coded identification assigned to each participant indicating type of participant and assigned number. Interview transcripts were identified in the same manner. This researcher had no access to any participant's identifying information. Hard copies of transcripts and analysis documentation were kept in a locked file cabinet.

Electronic copies of transcripts and demographic information, although de-identified, were stored in the researcher's password protected computer.

Human subjects considerations and confidentiality

IRB approval was obtained from The University of Texas at Austin IRB to conduct this secondary analysis of qualitative research data prior to any analysis procedures. (See Appendix B.) The Informed Consent provided by each subject prior to participation in the parent study included consent for data to be used in the future for research purposes not detailed in the consent form. It also contained assurances that data would contain no identifying information that could associate any subject with participation in the study.

Study trustworthiness

Whittemore, Chase, and Mandle (2001) discuss four major elements of trustworthiness within a qualitative descriptive study, including: (1) authenticity, or ensuring the voice of participants is treated with utmost importance; (2) credibility, the believability of results; (3) criticality, an accounting of each decision made throughout the research process; and (4) integrity, ongoing self-reflection of the researcher. The analytical steps involved in the secondary analysis, described above, endeavored to ensure authenticity and validity of the data first by virtue of this researcher having been involved with collection of the data, and also by immersion in the data through repeated review of the transcripts with analytic journaling to record additional impressions.

Credibility was addressed through ongoing expert review of methods and validation of data findings provided by the principal investigator of the parent study and other members of the dissertation committee. According to Schreier (2012, Ch. 4), credibility of the coding frame can be checked by ensuring that unidimensionality,

mutual exclusiveness, and exhaustiveness of the categories has been attained. Unidimensionality means that each category reflects only one idea or concept in the data. If each unit of coding only belongs to one subcategory within a given category or dimension, then the coding frame has achieved mutual exclusiveness. The coding frame is exhaustive if each unit of coding can be assigned to at least one subcategory. This is important because it indicates that the meaning of every coding unit has been considered in the analysis and no data have been overlooked or disregarded. Schreier suggests these elements be checked after the first few interviews have been coded so that any problems can be corrected, early in the coding process and all data can be coded consistently. Additionally, she states that consistency of coding, an element of credibility, can be checked by re-coding a certain portion of the segmented data at a different point in time from the first coding to ensure that coding remains consistent.

Criticality of the results was achieved by a clear audit trail including the analytic journal as well as analytic memos recording decisions made and justifications for those decisions through the analysis process. Integrity of the data was accomplished through a personal journal kept by the researcher to document personal thoughts and feelings, and possible biases, as they occurred throughout the analytic process, with careful review of these notes to ensure they did not enter into the interpretation or presentation of the data findings.

Reaching saturation of the data. Saturation is a secondary measure of validity in qualitative research; specifically, it speaks to the thoroughness of the research process (Whittemore et al., 2001). Similarly, Schreier (2012) describes saturation as a measure of reliability or credibility of the analysis method or coding framework. Thus, she suggests that if the coding frame is found to be consistent (through re-coding) and all categories and sub-categories have been addressed from the data or through the theoretical

framework, then saturation of the data has been reached. Whittemore and colleagues (2001) suggest that validity should be viewed within the context of the study purpose and circumstance.

This study attempted to obtain a complete and consistent picture of opportunities for resident involvement in health care planning and regimens through the analysis of data collected for a different but related purpose. It was hoped that this endeavor would be supported by the multiple perspectives in these data and the relevance of these participants' perspectives to the research questions. Limitations of secondary analyses include that additional participants cannot be sampled and additional questions cannot be asked of the participants (Greeno & Singer, 2010). Given those limitations, this study sought to achieve saturation by thoroughly analyzing all the given data and providing a vivid and full description of resident involvement opportunities as seen through the eyes of residents and the people who care for them.

Limitations of the study

Limitations to qualitative secondary analysis are similar to those of any secondary research analysis in that the sample is limited to the existing participants and the data are limited to the responses to questions asked in the parent study (Greeno & Singer, 2010). Additionally, in qualitative secondary analysis, the researcher is not in control of generating the data set and thus is not able to employ theoretical sampling directly responsive to the research questions (Szabo & Strang, 1997). New questions cannot be asked of the participants based on incompletely defined categories; member checking of newly discovered themes is rarely possible (Greeno & Singer, 2010); and flexibility of the methodology is limited (Greeno & Singer, 2010; Szabo & Strang, 1997).

As discussed earlier, the data collected in response to the parent study's interview questions "fit" the proposed study's research questions and provided a rich source of data. Although theoretical sampling or sampling to enrich category definitions was not possible, the existing dataset included data from a variety of participant groups theoretically expected to be key informants on this topic, i.e. administrators, physicians, APRNs, family members, and residents. Member checking was not possible but other means of trustworthiness were employed including an audit trail and expert review and validation of themes (sub-categories) by the principal investigator of the parent study (Heaton, 1998), and tested adequacy and reliability of the analytic tool or coding frame used in the secondary analysis (Schreier, 2012). Flexibility of the methodology was not an issue in this analysis, since the design of the parent study and the analysis method of the secondary analysis are well-accepted combinations in qualitative research.

Summary

The final project of this dissertation was a secondary analysis of qualitative data using a qualitative descriptive method and qualitative content analysis. The secondary analysis focused on chronic illness management opportunities available to residents in this setting and the factors influencing them. Wagner's Chronic Care Model was used as a sensitizing framework through which to view the data. Reasons justifying the appropriateness of conducting this secondary analysis were discussed. Immersion in the data, QCA techniques described by Schreier, including a planned initial coding frame, audit trail, and expert review, were presented as analytic and trustworthiness methods. Data management of de-identified data was described and limitations inherent in secondary analysis, as well as efforts to reach data saturation, were reviewed.

Chapter 2: A Systematic Review of the Literature on the Management of Type 2 Diabetes in the Nursing Home[1]

ABSTRACT

Purpose. Type 2 diabetes mellitus can be a severely debilitating disease. Large numbers of older-aged adults are being admitted to under-resourced nursing homes with this often time-intensive and costly diagnosis. The purpose of this systematic review was to determine the trends in diabetes management practices in nursing homes over the last decade examining the use of clinical practice guidelines and the evaluation of management outcomes.

Methods. Ten health care, legal and business databases were searched for articles written in English between the years 2000 and 2010 addressing diabetes management in long term care settings. They were analyzed to determine diabetes management characteristics, use of clinical practice guidelines, resident outcomes associated with different regimens, and implications for improved management and outcomes.

Results. Twenty studies from six countries and a combined sample of 779,707 residents, met the inclusion criteria. The majority of the studies described the frequency of various management practices and found rare clinical practice guideline adherence.

Conclusions. A lack of research relating management practices to health and quality of life outcomes and rare mention of resident preferences in determining the diabetes regimen were evident. Clear implications were found for improvement in diabetes management education for residents, families, as well as all health care providers in this setting.

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[1] Large portions of this chapter have been published as: Garcia, T.G. & Brown, S.A. (2011). Diabetes management in the nursing home: A systematic review of the literature. *The Diabetes Educator*, 37(2), 167-187, doi: 10.1177/0145721710395330.
(See Letter of Permission, Appendix C.)

INTRODUCTION

Type 2 diabetes mellitus affects nearly 24 million people in the United States, which translates to about 8% of the general population and almost 25% of the population aged 60 years and over (Centers for Disease Control and Prevention (CDC), 2008). The number of older-aged adults in the U.S. and worldwide is predicted to increase dramatically over the next two decades, especially in the 80 and over age category (Kinsella & He, 2008). This is likely to increase census numbers in nursing homes. In the second quarter of 2010, the Minimum Data Set (MDS), a periodic resident assessment instrument required by the Centers for Medicare and Medicaid Services (CMS), indicated that 33.3% of the 1.3 million residents in nursing homes were diagnosed with diabetes. Although type 2 diabetes, the most prevalent type, is associated with older age (CDC, 2008), many studies of diabetes in nursing homes do not refer to a specific type. For the purposes of this review, we assumed that diabetes in the nursing home was most likely type 2 and we refer to it as diabetes. Huang, O'Grady, Basu, and Capretta (2009) used a population-based model to predict that future diabetes prevalence in the elderly will increase from 8.2 million in 2009 to 14.6 million in 2034. With one-third of the nursing home population currently diagnosed with diabetes and with large increases predicted in the elderly population and in diabetes prevalence in the elderly, management of this disease in the nursing home setting is of great importance.

Diabetes is a complicated disease at any age but in the generally frail elderly in nursing homes, this illness becomes even more complex, precarious, and extremely expensive, if not managed competently. Older-aged residents in nursing homes often have multiple comorbidities, multiple medications, and high degrees of physical and/or cognitive impairment (Bourdel-Marchasson, & Berrut, 2005; Travis, Buchanan, Wang, & Kim, 2004). Care of an elderly resident with diabetes can be time-consuming, expensive,

and complicated (Huang et al., 2009). A patient often enters a nursing home with diagnoses that are considered more acute than diabetes (Zarowitz, Tangalos, Hollenack, & O'Shea, 2006), such as heart failure, stroke, Alzheimer's disease, or hip fracture, leaving the treatment of diabetes as a secondary, less immediate concern. Staff and medical care providers must negotiate myriad medications, treatments, needs, and wants of both the resident and family. Ensuring diligent diabetes management in often understaffed nursing home facilities, even under the best of circumstances, can be a daunting task.

Clinical practice guidelines for management of diabetes in a nursing home setting were first issued in 2002, and revised in 2008, by the American Medical Directors Association (AMDA, 2008). These guidelines stress the need for an individualized plan of care for each resident. A clinical algorithm is provided with the guideline outlining a systematic process of care including in-depth initial assessment of the resident and family, development of a goal-oriented care plan, and regular re-evaluation of the plan.

The American Diabetes Association (ADA, 2010) and the American Geriatrics Society (AGS, 2003) make recommendations for diabetes care in the elderly, although they are not specific to the nursing home facility (see Table 2). These guidelines stress strict glucose control in any older-aged patient who has greater than a five-year life expectancy, does not have multiple comorbidities, and does not have consistent problems with hypoglycemia. In a nursing home, these guidelines are difficult to implement because of the diversity of the population, high turnover rate among health care professionals (Anderson, Corazzini, & McDaniel, 2004), and overall fewer resources available than in traditional health care settings.

The purpose of this systematic review of the literature was to determine the current diabetes management practices and associated resident outcomes in nursing

homes in order to assess the need and best path for improvement. This review focused on research conducted in long-term care settings from 2000 to 2010, the time period when clinical practice guidelines for older-aged adults with diabetes emerged. The following questions were addressed: 1) *What are the characteristics of diabetes management practices in nursing homes?* 2) *How often and how closely are clinical practice guidelines used to guide diabetes management?* and 3) *What are the effects of different management practices on resident outcomes?*

METHODOLOGY

Search strategy. Ten databases most relevant to the topic were searched via the world-wide web including: Web of Science, CINAHL, PubMed, The Cochrane Library, ProQuest Dissertations and Theses, PsychINFO, JSTOR, LexisNexis Academic, Academic Search Complete and Business Source. Search terms in different combinations were used: *diabetes, diabetes mellitus, type 2 diabetes mellitus, NIDDM, non-insulin dependent diabetes mellitus, management, outcomes, nursing homes, long-term care, elderly* and *geriatric*. Approximately 30% of the initially screened-in studies were located through bibliographic searches of articles resulting from the original database search.

Studies were included if they were: 1) set in a nursing home or long-term care facility providing diabetes care to adults ≥ 60 years of age; 2) published/reported between January 2000 and March 2010; and 3) written in English. Unpublished theses and dissertations as well as quantitative and qualitative designs were included in order to generate the most comprehensive review. Studies focused on drug management only were excluded because the content was beyond the scope of this review.

All studies obtained from the database search were filed within an electronic data management program. Each study was screened based on title, keywords, and abstract for

relevance to this review's research questions and evidence of meeting the inclusion criteria. The initial search identified a total of 523 articles after removal of duplicates (see Figure 1). An initial screen by title and abstract found 310 articles that did not specifically address diabetes management in older-aged adults or were primarily focused on drug interventions. A second screen of abstracts and full texts excluded 148 articles because they were reviews, editorials, tutorials, or focused on summarizing or analyzing clinical practice guidelines. An additional 45 articles were screened out because the setting did not involve a long-term care population. After screening was completed, 20 studies were identified that met the criteria for inclusion in this review of the literature (see Table 3).

RESULTS

Designs, instruments, and validity assessment

The methodological quality of the sampled studies was examined according to guidelines outlined by Fink (2005). The majority of the researchers used descriptive designs and several used more than one method to collect and validate data. Most researchers used convenience samples, except the researchers conducting database review, and one study by Gill, Corwin, Mangin and Sutherland (2006), which used a stratified and randomly selected sample in New Zealand. Three studies, including Sjoblom et al., (2008), Goldberg (2003), and Tariq et al. (2001), were quasi-experimental and used non-randomized designs. Because older adults, especially those aged 80 and over, and those in nursing homes, are underrepresented in clinical trials and experimental research (Williams, 2007), we opted for a more inclusive approach to this review and did not exclude studies failing to report specific validity measurements of instruments or detailed description of qualitative methods.

Table 3 shows the research designs and methodological instruments used in this sample of studies. Seventy percent used a retrospective, descriptive review of the resident's records. Five studies, e.g. Quinn et al. (2009) and Pandya, Thompson and Sambamoorthi (2008), also used a retrospective review of state or federal databases or claim information to help establish validity and gather additional data. Surveys were used by the authors of seven of the studies with the majority surveying directors of nursing. The remaining surveys were answered by physicians or nurse practitioners. Feldman, Rosen, and DeStasio (2009) used several of the above descriptive methods and sampled residents in nursing homes across six states in the U.S. Two additional studies by Gill et al. (2006) and Douek, Bowman, and Croxson (2001) used structured interviews in addition to retrospective chart review. Only Gil et al. conducted direct interviews with nursing home residents. The included studies analyzed interviews for content only and qualitative methods were not described. Instruments employed were primarily author created questionnaires, surveys, and chart review data sheets. All were created with input from diabetes experts and geriatricians and some were piloted on other samples.

Only three studies used a quasi-experimental design employing interventions. Goldberg (2003) and Tariq et al. (2001) used a time series design to examine the effects of regular diets versus no-concentrated sweets diets, no longer recommended by the ADA (ADA, 2007). Sjoblom et al. (2008), in Sweden, used a pre-test, post-test non-equivalent group design to determine if withdrawal of insulin significantly affected glycosylated hemoglobin (A1C) levels. The researchers of these quasi-experimental studies primarily described the use of standard measurement instruments such as calibration of glucose monitors and weight scales.

Characteristics of the samples

Researchers of 13 studies conducted retrospective reviews of medical records and their samples ranged in number from 17 to 50,427, totaling 64,449 residents with diabetes across all studies. Three studies involved analyses of data from the MDS including 138,726 residents. The two largest studies, by Allsworth, Toppa, Palin, and Lapane (2005) and Spooner et al. (2001), used the SAGE (Systematic Assessment of Geriatric Drug Use via Epidemiology) database, a large integrated database with access to CMS data. Researchers from 8 studies used face-to-face interviews or written surveys. A total of 382 health practitioners were surveyed and 64 were interviewed. Gill et al. (2006) were the only researchers that directly interviewed residents; they included a sample of 116 older-aged nursing home residents.

Diabetes prevalence was the most frequently reported statistic in the sampled studies (see Table 3). Across the 14 studies that measured diabetes prevalence, the rate ranged from 8.4% to 53%. The mean weighted percentage of diabetes prevalence over the 20 studies was 18.5% of the total sample of 779,707 residents. This is much lower than the documented 33.3% currently reported for U.S. nursing homes (CMS, 2010), perhaps due to this review's inclusion of studies conducted outside the U.S., where diabetes prevalence is lower.

The second most frequently reported statistic was gender. The average percentage of female residents in the 12 studies that reported gender was 69.2% out of a total of 87,493 residents in this combined sample. This is congruent with the national nursing home survey of 2004 that reported 71.2% of the population of U.S. nursing homes was comprised of women (Jones, Dwyer, Bercovitz, & Straha, 2009). Four studies reported the average number of comorbidities across their samples, ranging from 2.9-8.3 with a weighted mean of 7.0 comorbidities per resident with DM. Travis et al. (2004) used MDS

data to investigate the types of comorbidities common in those diagnosed with diabetes in nursing homes. They found 69% of residents with diabetes were also diagnosed with hypertension, 30% with depression, 26% with congestive heart failure and 23.5% with cardiovascular disease (stroke). Only two studies, authored by Horning, Hoehns, and Doucette (2007) and Gill et al. (2006), reported the average number of medications taken by residents, ranging from 7.5-10.5 with a weighted mean of 8.52 medications per resident. The national nursing home survey of 2004 reported 47.9% of residents took 9 or more medications each (Jones et al., 2009).

Characteristics of diabetes management regimens

The diabetes management regimen characteristics described by the researchers in this sample of studies are summarized in Table 4. Of the 14 studies reporting percentage of residents with diabetes taking insulin, the weighted mean percentage out of a total of 65,029 residents was 39%. Ten studies reported percentages of residents with diabetes who received no medications ranging from 5.4-47% with a weighted mean percentage of 44.6%. Therefore, this review found that roughly 40% of nursing home residents with diabetes in these samples were using insulin and more than 40% were using no medication to control diabetes.

Other glucose management strategies included the use of sliding scale insulin (SSI) and A1C monitoring. Although the use of SSI should be minimal and only temporary (AMDA, 2008), the weighted mean percentage of SSI use in the four studies reporting it, which involved a total of 10,385 residents, was 54.2%. This represents a large deviation from clinical practice guidelines. A1C monitoring, reported by only four studies with a combined sample of 517 residents, yielded a weighted mean percentage of

79.7%, making this aspect of diabetes management the most consistent with guideline recommendations.

Additional management strategies frequently studied included blood pressure monitoring, dietary restrictions, and routine foot or eye exams. Blood pressure was routinely monitored in 73% of residents sampled. The use of restricted diets was found in 72.4% of sampled residents, in spite of ADA recommendations against restricted diets in older patients with diabetes (ADA, 2007). Only 34.6% of residents sampled were receiving routine eye exams. Routine podiatry exams fared a bit better with a mean weighted percentage of 68.9%. This lack of clinical practice guideline adherence is further supported by McNabney et al. (2005) who surveyed 255 AMDA member physicians and found that 50% always ordered restricted diets, only 6-51% always ordered routine eye exams and 36-67% always ordered routine podiatry exams. Taylor and Hendra (2000) surveyed 70 directors of nursing in nursing homes in the U.K. and found that all residents with diabetes were on restricted diets and only 56% received routine foot exams.

Despite the need to screen for undiagnosed diabetes being listed as the first step in quality diabetes management in most diabetes clinical practice guidelines; only one study in this sample directly addressed this issue. Hauner, Kurnaz, Haastert, Groschopp, and Feldhoff (2001) conducted a study in Germany that found approximately 39% of residents not previously diagnosed with diabetes had an A1C of greater than 6.1%. Although, this may not represent undiagnosed diabetes in the entire 39%, it is interesting that only one group of researchers in this review considered diabetes screening a primary focus of study in the nursing home.

Use of clinical practice guidelines

Table 3 lists the studies that referred to or used clinical practice guidelines as a comparison measure for described diabetes management practices. It also lists the specific guidelines referenced. All but two studies referenced practice guidelines in some way. Three studies gave specific percentages as to whether guidelines were followed and these percentages ranged from 87% to 0%. Table 3 also includes a summary of the conclusions drawn by the investigators. Seven of the 20 study investigators, e.g. Holt, Schwartz, and Shubrook (2007) and Horning et al. (2007), concluded that clinical practice guidelines were not closely followed or would improve quality if they were more closely followed.

Diabetes management associated resident outcomes

Only five of the 20 studies, including Feldman et al. (2008) and Pham, Pinganaud, Richard-Harston, Decamps, and Bourdel-Marchasson (2003), discussed resident health outcomes, complications, or adverse events associated with diabetes and none related these outcomes to different aspects or types of diabetes management regimens. Thus, although these studies provide information as to the prevalence of adverse events such as hypoglycemic episodes, hospitalizations, skin ulcers, infections, or amputations, they do not associate these occurrences with management characteristics and thus provide little evidence as to best practices.

Finally, the studies, although varied in purpose, often included similar conclusions and recommendations. Diabetes education for staff, health care practitioners, residents, and families was most frequently recommended. Better adherence to clinical practice guidelines was stressed as well as the need for further outcome-related research.

DISCUSSION

This review of the literature consisted of 20 descriptive studies primarily focused on describing the prevalence of diabetes, the frequency of different monitoring and treatment practices, and the rates of adherence to practice guidelines in nursing home settings. A consistent lack of adherence to referenced clinical practice guidelines was found across studies. This finding is similar to that found by Berlowitz et al. (2001) who surveyed employees of Veteran Administration nursing homes and found that although most were familiar with practice guidelines, less than 50% stated the guidelines had been adopted by the facility. Colón-Emeric et al. (2007) looked at the general use of clinical practice guidelines in nursing homes and found several barriers preventing or delaying the use of guidelines in this setting, including limited facility resources and conflicts with family and resident goals. These findings raise the question, could this lack of adherence to guidelines be a reflection of individualized management already in practice? Clearly, the continued widespread use of SSI and restricted diets is a reflection of outdated practices; but the great numbers of residents not receiving any medication or routine monitoring may possibly reflect individualized care in process.

In support of this hypothesis, the study conducted by McNabney et al. (2005) surveyed physicians, allowing them to characterize their management practices for three different patient scenarios. They found a distinct difference in the physician practice characteristics based on the patient situations described. Thus, individualized plans of care may be present in facilities but not well- documented or not evident to researchers. This possibility should be researched further to distinguish between inadequate care and appropriate individualized care with inadequate documentation.

Clement and Leung (2009) reviewed the literature on diabetes management in nursing homes and conducted pilot projects in Canadian nursing homes. They identified

barriers to quality care much the same as the studies in this review, such as outdated practices, knowledge deficits by both physicians and nurses, and lack of communication among all members of the health care team. Also, like the conclusions contained in many of the studies included in this review, they recommended a greater focus on patient outcomes to develop a scientific basis for guidelines and to determine the relationships between adherence to guidelines and glycemic control and adverse events such as falls, skin ulcers, and hospitalizations.

This review has several limitations. All the studies found regarding diabetes management in the nursing home setting were those reported during the last decade only. None were excluded based on validity or quality because of the paucity of studies on this topic and because researchers often used triangulation to validate their data and described their own limitations. Although weighted average percentages of management characteristics were provided, their usefulness and generalizability are limited due to the primary use of convenience sampling by these researchers, the heterogeneity of the samples, and the exclusively descriptive nature of the studies.

The most significant gap found in the literature was the lack of research into the relationship between diabetes management practices and outcomes of care. The recommendations of many of these investigators were for further study clarifying the different types of diabetes management and the relationship between these specific types to outcomes such as disease complications, adverse events, and quality of life. The literature was also lacking in the inclusion of the resident and family perspectives on diabetes management practices and regimens, as stressed by clinical practice guidelines for the nursing home setting (AMDA, 2008). Several structured interviews were conducted in the studies but mostly with practitioners and nursing home staff; and none were truly qualitative in method or rigor. Huang, Gorawora-Bhat, and Chin (2005)

conducted qualitative interviews of elderly residents with diabetes residing in the community setting to determine their diabetes management goals. They concluded the primary goal of these elderly individuals was maintaining independence. It is not known how these results might differ in the nursing home population. Residents and families are the most important members of the nursing home team and their preferences are crucial when individualizing diabetes care in this setting.

IMPLICATIONS

The resounding implications of this review for diabetes educators were: the need for increased and improved education of residents, families, and all involved health care providers to improve diabetes management; the need for additional research addressing the relationship between different types of management and resident outcomes; and giving voice to the experiences of residents with diabetes in nursing homes. Several investigators emphasized the need for more frequent and better staff education in order to improve the quality of care received by nursing home residents. Berry and Raleigh (2004) called for more research into types of practice patterns and several others suggested the need for outcomes of specific practice patterns to determine best practices and to provide evidence for guidelines. Finally, this review asserts a definite need for further research to determine if findings interpreted as a lack of adherence to guidelines are actually a lack of adequate documentation of appropriate individualized diabetes care for the elderly in nursing homes.

CONCLUSION

The escalating importance of the need for high quality management of diabetes in the nursing home setting is evident in the growing numbers of older-aged adults worldwide and the competing growth of diabetes, in almost epidemic proportions, in this

population. Under-resourced long-term care facilities bear the burden of managing this growing health issue in the frail elderly. In order to provide optimal quality of life and to avoid costly progression of diabetes, clinical practice guidelines must be incorporated into facility policies and individual plans of care must be implemented and clearly documented.

Chapter 3: Involvement of Older-aged Adults in Chronic Illness Care Decisions: A Metasynthesis

ABSTRACT

Purpose: This qualitative research synthesis aimed to describe the perceptions of current older-aged community or facility-dwelling patients regarding involvement in chronic illness care decision-making to facilitate meeting the demand by the future older-aged generation for more person-centered chronic illness care.

Design: A metasynthesis of the qualitative literature was conducted.

Sample: Included studies sampled chronically ill persons ≥ 50 years of age with minimal cognitive impairment and used a qualitative methodology describing older-aged persons' perceptions of involvement in chronic illness care decisions.

Methods: Five health databases were searched for terms including: *decision-making, person-centered, older-age, nursing home, chronic illness*, and *involvement*. Studies were appraised and included based on degree of data interpretation. Domain and comparative analysis techniques were used. Trustworthiness was maintained through team discussion and audit trail.

Findings: From a final sample of 7 studies, 4 themes emerged: (1) *Being recognized because I matter*; (2) *Awareness of importance*; (3) *Empower through connections and opportunities*; and (4) *Time is precious*. Inadequate time and commitment by health care providers emerged across studies as the greatest perceived determinants of involvement in decision-making.

Conclusions: Some older-aged, chronically ill adults, regardless of residence, desire involvement in health care decisions, benefit from involvement, and may suffer from non-involvement.

Implications: Increased commitment of time by health care providers is necessary to improve the provision of person-centered care for current and future generations of chronically ill older-adults. Future research should investigate the effects of APRN's on the health and quality of life outcomes of this growing population.

INTRODUCTION

In past generations, as people have aged and become ill and disabled, they have tended to become less involved in their health care decisions, either due to cognitive impairment, loss of interest, or loss of autonomy in institutional settings (High & Rowles, 1995). The Baby-boom generation, living longer and with more chronic disease issues, fosters a generational philosophy of staying young, strong, independent, and in control for as long as possible (American Hospital Association (AHA) & First Consulting Group (FCG), 2007). This new philosophy of the coming older generation may greatly challenge health care providers in the gerontology field. The challenge stems from three major sources: (1) a general shortage of gerontological health care providers available (Katz, Karuza, Kolassa, & Hutson, 1997; Peterson, Bazemore, Bragg, Xierali, & Warshaw, 2011); (2) a dramatic increase in the number of patients who demand more individualized and autonomous care (Kietzman, 2012); and (3) soaring costs of health care and long-term care (Calmus, 2013; Mettler & Kemper, 2007).

For older adults with long-term chronic illnesses, the treatment of symptoms and prevention of complications may occupy a large portion of their day-to-day activities. The person-centered care movement strives to empower capable and interested patients to make their own health-related decisions, giving them more control over their daily lives (Koren, 2010). Advanced practice registered nurses (APRN's), especially gerontology specialists, are educationally and philosophically prepared to facilitate patient-centered

care for older-aged persons with chronic illness, through independent and collaborative practice (Counsell, Callahan, Buttar, Clark, & Frank, 2006; Lloyd, 2011; The Times Editorial Board, 2013). APRN's providing long term chronic illness care to older-adults include the Adult Gerontology Clinical Nurse Specialist, the Adult Clinical Nurse Specialist (CNS), the Family Practice Nurse Practitioner, and the Adult Gerontology Nurse Practitioner. The question as to whether health care professionals providing care to older-aged adults in the near future are prepared to handle the predicted onslaught of patient demand for greater decision-making autonomy looms before us. This metasynthesis aimed to describe the current older generations' perceptions of health care decisional involvement, through a synthesis of the qualitative literature conducted over the last 15 years presenting patient perceptions of involvement in health care. These perceptions may illuminate future steps needed to meet the expectations of a more demanding generation of patients.

BACKGROUND

Chronic illness in older age

People are living longer due to advances in health care and healthier lifestyles; but longer life allows greater time to acquire and suffer from chronic disease (Merck Institute of Aging & Health, The Centers for Disease Control and Prevention (CDC), and the Gerontological Society of America, 2004). Heart disease, cancer, chronic respiratory conditions, stroke, Alzheimer's disease, and diabetes were the leading causes of death in older-aged adults in 2009 (CDC, 2009). Obesity is expected to affect 1 in every 3 older adults by 2030 with arthritis afflicting 1 in every 2 adults (AHA & FCG, 2007). Combined with the approximately 30% of older-aged people injured by falls each year

(Fuller, 2000), these illnesses and disabilities will increase the number of older adults with chronic care needs in the future.

Meeting chronic illness care demands

Although, it has been established that not all older-aged people want to be involved in medical decision-making (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Belcher, Fried, Agostini, & Tinetti, 2006; Wetle, Levkoff, Cwikel, & Rosen, 1988), researchers have found a significant percentage that do have an interest in taking either an active or collaborative medical decision-making role (Maly, Umezawa, Leake, & Silliman, 2004; Rodriguez, Appelt, Switzer, Sonel, & Arnold, 2008; Vieder, Krafchick, Kovach, & Galluzzi, 2002). Given that the Baby-boom generation is highly educated and computer-literate (Zickuhr & Madden, 2012), it is likely that patient-centered chronic illness care for the elderly will soon be in higher demand (AHA & FCG, 2007).

Due to this expected increase in demand for person-centered medical care by older-aged adults, a shortage of medical care providers specializing in gerontology, and higher costs associated with care, APRN's may become critical to meeting this demand (Institute of Medicine (IOM), 2008; IOM 2010; Mezey et al., 2005). Gerontology APRN's are prepared to manage the health care needs of older adults, providing medical treatment, rehabilitation, and end-of-life care, as well as serving as health care educators to patients, families, and long-term care staff, and taking the role of patient advocate and gerontological research consumer (St. Pierre & Conley, 2010). Physicians and nurses specializing in gerontology are few. Physicians practicing in long-term care report spending only about 4% of their time in nursing homes (Katz et al., 1997), while APRN's practicing in nursing homes have been found to spend more time and provide more visits

with residents than physicians do (Bakerjian & Harrington, 2012; Farley, Zellman, Ouslander, & Reuben, 1999). APRN care has resulted in equal or improved quality of care (Aigner, Drew, & Phipps, 2004; Intrator, Zinn, & Mor, 2004; Ryden et al., 2000), patient, family, and physician satisfaction (Rosenfeld, Kobayashi, Barber, & Mezey, 2004) and lower costs (Kane, Keckhafer, Flood, Bershadsky, & Siadaty, 2003; Intrator et al., 2005; Kane, Flood, Bershadsky, & Keckhafer, 2004).

The aim of this systematic qualitative review was to synthesize the qualitative literature conducted over the last 15 years, exploring the perceptions of older-aged persons, in the community and in nursing homes, regarding their involvement in chronic illness care decisions. The research questions were: *From a chronically ill older-aged person's perspective:* 1) *What does it mean to be involved in health care decisions?* 2) *What does it mean not to be involved?* 3) *What are the barriers and facilitators to involvement in health care decisions?*

DESIGN AND METHODS

Design

A qualitative metasynthesis of the literature using domain analysis and comparative analysis techniques was conducted. Metasynthesis is a systematic review and integration of qualitative literature, analyzing each study's findings to construct a new, intensified, qualitative interpretation of findings across studies (Sandelowski & Barroso, 2003). Advocates of qualitative metasynthesis assert that it is an excellent means to move qualitative research closer to clinical practice, making it a useful and important component of evidence-based practice literature (Sandelowski & Barroso, 2007). The methodological processes for metasynthesis are continuing to evolve, but most experts in the field agree upon the utility of methods included in this study. They were: (1) a

comprehensive literature search; (2) appraisal based on degree of data transformation (interpretation); (3) classification of studies; and (4) synthesis of findings (Sandelowski & Barroso, 2007). Trustworthiness was maintained through: (1) clarification of methods; (2) team discussion of data transformation appraisal and coding; and (3) an audit trail of coding and thematic decisions.

Search strategy

Various combinations of the following terms: *person-centered, older age, nursing home, long-term care, chronic illness, involvement, preferences, perceptions, autonomy*, and *decision-making* were systematically searched using five computer databases including, PubMed, Web of Science, MedLine, CINAHL, and PsychINFO. Studies were included if they: (1) were written in English; (2) were published after 1996; (3) sampled chronically ill persons ≥ 50 years of age with mild or no cognitive impairment; and (4) used a qualitative thematic or interpretive methodology that described or explained older-aged persons' perceptions of involvement in chronic illness or health care decisions. Of 539 patients sampled in the studies, 3 were aged 50-60 years (all from one study conducted in The Netherlands) (Schoot, Proot, ter Meulen, & de Witte, 2005). The patient participants from this study were specially selected because they were members of an association of people living with chronic illness or disability. They were included in this sample because of the increasing number of middle-aged, chronically ill and disabled persons living in nursing homes and in the community (Miller, Pinet-Peralta, & Elder, 2012), who may be facing many of the same decisional involvement issues experienced by older adults.

Data transformation appraisal

Studies were appraised by degree of researcher transformation of data (on a scale of 1 to 5 - see Table 5), as evidenced by going beyond the data, describing interpreted themes, and using them to explain the data (Sandelowski & Barroso, 2007). Studies were included if they were appraised by both researchers as level 3 or above. This required studies to include exemplars of actual participant quotes and to provide in depth explanation of categories and/or themes, using themes or theory to interpret or further explain the data. Assessing the degree of data transformation ensured that only studies with interpretive findings were included. This was done to remain true to the definition of metasynthesis: an interpretive integration of interpreted research findings (Sandelowski & Barroso, 2007). Because consensus on quality criteria for qualitative studies has not been reached (Sandelowski & Barroso, 2007), no study was excluded based on the rigor of the specific qualitative methodology used.

Data analysis

Domain analysis

As described by Spradley (1979), domain analysis is an ongoing, iterative process by which symbols (words and phrases used by the participant or researcher to describe the participants' perceptions) are analyzed to determine cultural meaning. Using domain analysis in metasynthesis allows underlying relationships and concepts present in each study, but not necessarily directly stated, to emerge when contrasted across studies (Sandelowski & Barroso, 2003). The text of the findings from each study was searched for relevant terms and then organized into domains. A domain consisted of a *cover term* and *included terms*. The included terms are related to the cover term by a semantic

relationship such as "*x is a kind of y*," where "*x*" is the included term, "*is a kind of*" is the semantic relationship, and "*y*" is the cover term.

A worksheet filled with domains was prepared from reading and re-reading the findings (Spradley, 1979). The analysis was built by adding to the internal structure of each domain, asking different types of questions from the data prompted by gaps in the analysis. Once all included studies were analyzed, the domains were organized into larger categories, chosen by the researchers based on the research questions and the data. These categories were: (1) meaning of involvement; (2) meaning of non-involvement; and (3) barriers and facilitators to involvement. Each of the domains was categorized based on whether it referred to or explained any of the larger categories. The categorized domains were then searched for common themes.

Comparative analysis

Each study's findings, including described themes, participant quotes, discussion of findings, and conclusions, were read and re-read and a comparative table was created, including the reviewers' impressions of each study. Further comparison between the themes resulting from the domain analysis and each study's thematic findings was done to ensure congruence among all studies and to search for any additional interpretive, or overarching explanatory themes across studies, using a form of comparative analysis to synthesize the data (Sandelowski & Barroso, 2003).

RESULTS

Search results

Initial searches yielded a total of 2047 articles, reduced to 1020 after duplicate removal. (See Figure 2.) Search by title and abstract for inclusion criteria, decreased the number of studies to 315. Further review of full text articles for inclusion criteria yielded

a sample size of 11 studies. Bibliographic searching of pertinent articles, added 5 studies, making a total of 16 studies included in the initial review. Nine of the 16 studies were excluded based on data transformation appraisal, i.e. excluded studies did not include exemplars of actual participant quotes and did not provide in-depth explanations of categories and/or themes that attempted to interpret or further explain the data. The remaining 7 studies presented rich descriptions of interpretive themes and concepts and included participant quotes for further clarity.

Classification and data transformation appraisal results

Table 6 shows the location, purpose, setting, sample characteristics, design, method, theory, typology of findings, appraisal value, and major findings or themes for each of the included studies. All the studies presented the participants' views on various aspects of decisional involvement in health care: 2 studies (Belcher et al., 2006; Hughes & Goldie, 2009) explored involvement in medication-related decisions; 2 explored involvement in primary health care and relationships with physicians and nurse providers (Bastiaens et al., 2007; Schoot et al., 2005); another examined preferences for discussing life and health goals with medical providers (Schulman-Green, Naik, Bradley, McCorkle, & Bogardus, 2005); another focused on how participants coped with multiple chronic illnesses (Loffler et al., 2012); and another explored change in decision-making autonomy in the nursing home over time (Shawler, Rowles, & High, 2001). The different but related study goals provided rich data for interpretation of the research questions.

Characteristics of the samples and settings

The sample included 541 chronically ill older-aged persons (57% female), ranging in age from 50 to 97 years, residing in the community or in nursing homes. Most were over 70 years of age and resided in the community (97%). One of the nursing home

studies (Shawler et al., 2001) was an exemplar case from a large, 3-year, ethnographic study including perspectives from multiple nursing home stakeholders. The case study was included in this review, instead of the larger study, because its major focus was decision-making from the perspective of the resident. Three other studies (Hughes & Goldie, 2009; Schoot et al., 2005; Schulman-Green et al., 2006) included data from family members or clinicians. Although the researchers' overall findings, which included perspectives of participants other than those of patients, were included in the analyses, the focus of this study was primarily on the perspective of the patients.

Qualitative synthesis of study findings

Domain analysis yielded the following themes: (1) *Being recognized because I matter*; (2) *Awareness of importance*; and (3) *Empower through connections and opportunities*. Comparative analysis of the above themes to each study's themes and concepts yielded a final overarching theme: *Time is precious*. These themes explained, from the perspective of the older-aged patient with chronic illness, how time spent by the health care provider may have an effect on level of self-esteem, which may then affect his/her ability and interest in involvement and the degree to which he/she feels recognized as an individual whose opinions matter. (See Figure 3.)

Theme 1: Being recognized because I matter

Participants across studies described the meaning of being involved in health care decisions as feeling confident, informed, and understood. By far, the strongest message was the feeling of importance that accompanied being recognized as an individual whose opinions mattered (Schoot et al., 2005). This recognition was described in reference to provider-patient interactions where the provider listened to the patient:

> Well he is a good listener. He is observant. Then when I have told my bit of the tale he will ask questions for clarification and then he will give his view on things (Bastiaens, 2007, p. 37).

Interwoven in this theme of need for recognition as a unique person was the concept of time. Listening to patients and getting to know them as individuals by engaging in friendly and unrushed dialogue were gestures that communicated and recognized worth, importance, and respect. This nurturing kind of relationship was possible if quality time was invested by health care providers and if the relationship remained consistent over a period of time.

Theme 2: Awareness of importance

Not being involved in health care decisions meant feeling inferior, angry, frustrated, humiliated, insulted, isolated, and lonely. Belcher et al. (2006) asserted that patients who did not take part in decision-making felt powerless because they did not believe their opinions were important or made a difference: "…I don't think I could be much of a help. I don't think anybody would take me seriously enough…" (p. 300). The researchers described participants as not being aware of their importance to the process of health care decision-making.

The studies found that barriers to involvement included self-perceived characteristics such as old age, forgetfulness, and physical frailties that added to the notion of inadequacy and unimportance: "I am an old man; I do not memorize anything… The cholesterol and the blood, I really do not know much about, and then I forget, because I do not catch it at all" (Bastiaens et al., 2007, p. 38).

Other researchers found that participants just believed, trusted, or expected the provider was the expert and had authority over them in medical situations: "I will always do what they recommend. I have great faith in them. I believe in them and I do what I'm told to do" (Schulman-Green et al., 2006). Belcher et al. (2006) found that if a patient

trusted his/her provider, s/he may defer all decisions to them without question: "Well I put my hands in my doctor's hands, and if he tells me this is good for me than I believe him" (p. 300). It seemed the participants felt their preferences and opinions were less important than those of health care providers.

On the other hand, some researchers described participants who did believe they were important to the decision-making process and attempted to facilitate their involvement by gaining parity with providers through reading, internet searching, or just asking questions, placing themselves in a better position to take part in their health care and better control their illnesses (Bastiaens et al., 2007; Belcher, et al., 2006; Loffler et al., 2012):

> I read a lot of magazines and newspapers and quite often they include reports about migraine and I know 100% certain how I need to react… I read a lot about my sickness in books (Loffler et al., p. 5).

Yet other residents, regardless of living situation (nursing home or community setting) were described as much more passive. Authors of the nursing home study on medication decision-making hypothesized this passivity was due to the generation of this population ("The Silent Generation,") or was induced by several years of institutionalization (Hughes & Goldie, 2009). This study found the majority of their participants accepted complete control of their medications by providers with little hesitation and that some were unaware they could even play a role: "I just take what I am given. I believe in doing what I am told" (p. 512). This may reflect disinterest by the patient or could be echoing the feelings of inferiority and unimportance discussed above.

Similarly, another medication decision-making study conducted in the community setting found that many participants did not want decisional involvement and some felt they could not participate due to lack of knowledge, "I don't know anything about them.

How can I make a decision" (Belcher et al., 2006, p. 300)? Others felt they should participate, but only enough to "know about their medications" (p. 300), as opposed to actually taking part in active decision-making. Thus, regardless of living situation, participants in these two studies were largely uncomfortable with making decisions regarding their medications.

Theme 3: Empower through connections and opportunities

What hindered or facilitated patient involvement in health care decisions? Across studies, this question could be answered with one central concept: quality of communication. The most commonly voiced barrier to patient involvement discussed by researchers was the poor quality of the provider-patient interaction, which communicated provider preoccupation and lack of interest in the relationship, i.e., being too disconnected and not invested in the relationship. "Well it all depends on how the doctor reacts. Some doctors are just so selfish you don't want to ask them nothing… like they don't care, you know…" (Belcher et al., 2006, p. 301).

A focus by providers on numbers, i.e., lab values and test results, rather than on patients, was related by Belcher et al.: "His one goal was to see a certain number and that was it" and "Certain doctors are robots. They're statistical robots" (p. 301).

Again, the issue of time pervaded this theme. Participants felt rushed during clinical encounters, as though providers were too busy or had other more pressing priorities:

> I'd like the doctor to know me, but you can't do that now. You don't have the chance of a snowball in hell. You go to see a doctor, you're out in 10 or 15 minutes. He's reaching for his prescription pad or something (Schulman-Green et al., 2005, p. 148).

Although researchers focused on participant complaints about provider communication and interactions, they also stressed what providers could do to facilitate better patient involvement. Overall, they expressed a need for encouragement, guidance, and support from the provider in order to help participants become more involved; participants voiced a need for the provider to be a "developer of client competencies, giving them the opportunity to participate in care" (Schoot, et al., 2005, p. 175).

> So I don't know whether it is possible for a lay person to be involved in their medication unless the doctor sits down and says to them, well we have a choice of doing A, B, and C. And then outlines what A, B, and C are, and then offers them a choice (Belcher et al., 2006, p. 301).

Participants acknowledged a lack of knowledge and a need to learn so that they have the opportunity to express educated opinions (Schoot et al., 2005):

> Indicate how the procedures work, provide me for example with an indication, because the health care service is like a jungle, show me what the options are and what I can choose (p. 175).

Another aspect of this theme was found to be more central to the nursing home studies and not as dominant in the community studies: the conflict over control. The nursing home studies were more focused than the others on the influences that the facility, providers, and family had on resident involvement in decision-making. These findings centered on the beneficent paternalism of providers and family members and how this paternalism led to resident perceptions of loss of control in health-related decisions. Shawler et al. spoke of nursing home providers' "well-intentioned" (p. 619) withholding of information from residents in health care decisions where the resident was fully aware decision-making control was being "benignly removed from her as she became more frail and vulnerable" (p. 619).

Similarly, Hughes & Goldie focused on health professionals' unwillingness to give up control of medication choices and medication administration because of possible

interference with the routine and organization of the system that promoted safety and security for residents and families. Thus, the perceived need of providers and family members to control medical decision-making in the best interests of the resident provided additional barriers for nursing home residents to be meaningfully involved in their chronic illness care decisions. The overarching theme of "time being precious" is present here as well. The nursing home studies encouraged stakeholders to weigh the consequences of favoring institutional-type routines to protect resident safety and security over more *time-consuming*, routine-breaking, systemic changes that could lead to more resident-centered, albeit, less secure, outcomes.

Synthesizing overarching theme: Time is precious

Throughout all studies there was a recurring expression of lack of time, resulting in one overarching theme that impacted involvement of older-aged persons in daily health care decisions and connected all the other themes and studies together: time is a precious commodity in health care. The data and interpretations from these studies were filled with terms, quotes, and expressions alluding to time, usually, a lack of time, and often, the passage of time. In a culture where everything moves quickly with or without those afflicted with chronic illness and disability, some may begin to believe they do not matter or that their needs are somehow less important than the needs or priorities of others. For example, Schulman-Green et al. reported that participants would like to discuss health care goals with their providers but the interest of the provider is on hurrying up the visit:

> They don't have time for that. I've heard a doctor say when you try to give him a list of some things [personal health goals], well, he'll say, "Well, what troubles you today?" Not a general thing, but what today. Which toe hurts today (p. 148)?

Passage of time as a barrier to taking part in health care related decisions was discussed by Shawler et al. who described a participant experiencing the need to make more health decisions as her frailty increased over time:

> … a trajectory of growing decisional dependency... As time passed, Edna's involvement was marginalized as her autonomous daily health care decision making met with progressively less support and cooperation from other members of the decision-making constellation (pp. 618-619).

These studies revealed that there are members of this population who can and want to be involved in their health care decisions but standing in their way are self-perceived notions of unimportance, incompetence, and inequality. These ideas possibly originate from and may be reinforced by health provider and health facility actions aimed at providing high efficiency quality care and safety. These goals are laudable and necessary but the steps taken to achieve them must include the recognition, self-esteem, and informational needs of the patient. This can only be done by taking the time necessary to communicate with patients effectively, compassionately, and consistently.

DISCUSSION

This metasynthesis of studies has explored the meaning of involvement in health care decision-making to older persons with chronic illnesses residing in the nursing home setting and in the community. Being involved in health care decisions was described as being recognized as an individual whose thoughts and opinions mattered. It communicated being considered worthy of inclusion in a conversation of high importance and significance. This view differs from the general intent of "shared decision-making," where involvement means actually taking part in a decision that affects a health outcome (Charles, Gafni, &Whelan, 1999), such as opting out of a hospital admission and deciding to be treated for pneumonia at home or in the nursing home. Although feelings

of increased confidence and self-reliance were described, they were rarely associated with the right to an autonomous decision, but rather were related to feeling trusted and included in the decision-making process. This discrepancy in definition was also noted by two of the included studies' authors, Bastiaens et al. (2007) and Belcher et al. (2012). These studies rarely mentioned what patients perceived were the consequences or outcomes of involvement in decision-making.

Exclusion from care planning conversations was described as conveying a message to patients that they were less important or of lower priority than other matters. They expressed that it conveyed feelings of inferiority, inequality, and powerlessness. It compounded the natural losses of aging and illness, and reinforced the loss of identity induced by chronic illness routines. It was expected that nursing home residents would be more descriptive of being left out of decisions than community-residing patients, since institutionalization is often associated with greater loss of autonomy. It was found, however, that both populations were able to describe, fairly similarly, the emotions associated with exclusion from health care decisions. It is possible that the older age of most of the community dwelling patients and the fact that all were afflicted with more than one chronic illness, confined them, and placed them in a position, somewhat similar to that of nursing home residents.

Barriers to involvement across studies were described as: participants' self-perceived cognitive and physical frailties, lack of information or education, unquestioned trust in the provider, and the belief that requests would not be taken seriously. Another major barrier was seen as providers' reluctance to invest the time and effort necessary to make a connection with the patient. These findings agree with Ashworth, Longmate, and Morrison (1992) who undertook a study of the phenomenology of patient participation in health care. They concluded that in order to ask patients to participate in their own health

care, their sense of identity and self-esteem must be preserved. The health care provider must ensure that patients feel as though they are members in the "stock of knowledge at hand" (p. 1437), i.e., that they understand, from their own perspectives, the choices and alternatives, and do not feel as though their knowledge level prevents them from making an informed decision. They must feel that their contribution to the decision-making process is worthy of consideration.

A barrier that seemed to predominate in the nursing home studies only was that of beneficent yet paternalistic control by the nursing home system, health care providers, and family members. Although resident perceptions were presented, both nursing home studies focused on the reluctance of other stakeholders to give up control of chronic illness decisions, preventing residents from recognizing they could be involved in decisions and from exercising any meaningful involvement in care decisions. Similar findings of powerlessness among nursing home residents were described by Nystrom and Segesten (1994) who found that although residents were considered experts on their own lives, this expertise only applied to the knowledge of their pre-nursing home life and that their current medical care should be decided by health care experts.

Facilitators of decisional involvement were described as patients striving to learn more and be better prepared to understand health care through reading, asking questions, and persistent assertion of needs. Improved communication, connection, and commitment by the provider to the patient through investment of quality time, active listening, the persistent encouragement of questions, and the provision of understandable explanations were also indicated as major facilitators. The majority of these facilitating factors were found in the community based studies. The nursing home studies stressed the larger goal for providers of empowering residents rather than controlling them, when it came to health care decisions (Shawler et al., 2001; Hughes & Goldie, 2009).

Time as a precious commodity was considered to be the overarching theme that ran through all the others and across studies. Lack of time perceived by participants in their interactions with providers was described as a barrier to patient involvement. In this synthesis, the concept of time, whether it was a manifestation of provider detachment or a product of an economically driven health care system, emerged as the greatest perceived determinant of resident involvement. This synthesis revealed that capable and interested patients, whether initially motivated to be involved in their care or not, could possibly become involved, stay involved, or become more involved, if encouraged. Encouragement occurs when providers and family members have the resources and the desire to consistently spend the time necessary to cultivate a trusting, comfortable relationship recognizing the patient as a unique individual worthy of deliberate explanations, patient responses to questions, and modification of health regimens according to patient preferences. Because encouraging participation of patients who do not desire to be involved has been found to cause stress and/or to be unethical (Rodin, 1986; Waterworth & Luker, 1990), care must be taken to determine each individual's desire for involvement prior to initiating a plan of care.

The need expressed by these studies for more time to be spent with patients in order to improve patient-centered care is not new, nor is the implication that APRNs can be instrumental in fulfilling this need. Gerontological CNS's have implemented care models found to decrease geriatric syndromes, decrease cost, and increase time spent with patients (Conley, Burket, Schumacher, Lyons, DeRosa, & Schirm, 2012). Nurse practitioners caring for patients with chronic illness spend more time, have better patient satisfaction, and have equal if not better outcomes than care provided by physicians (Abdallah, 2005; Brown & Grimes, 1995; Kappas-Larson, 2008). Thus, the opportunity for greater decision-making involvement through person-centered care and recognition of

the importance and individual preferences of the patient can be greatly enhanced by the APRN workforce in gerontology.

LIMITATIONS OF THE STUDY

The findings of this metasynthesis were limited by the small number of studies available. The inclusion of the studies conducted in the nursing home enriched the data and allowed a broader understanding of this phenomenon across residential conditions. Not all older-aged people are cognitively capable of or even if capable, have a desire to make decisions or to be included in decision-making conversations (Funk, 2004), thus these findings are confined to the populations similar to those in these studies.

IMPLICATIONS AND CONCLUSIONS

Older adults who desire health care decisional involvement may benefit from it in ways that affect quality of life, while being left out of these conversations may cause emotional harm and contribute to loss of autonomy. Future work is needed to elaborate on how older adults perceive the purpose of involvement in order to assist in designing interventions to meet their needs and desires. This work stresses the need for studies measuring the relationships between time spent in provider-patient interactions, quality elements of those interactions, and resulting patient quality of life and health outcomes. The APRN can be a major contributor in assessing and meeting the decisional needs of current and future generations of older patients with chronic illness. Future studies should include the measurement of economic and patient outcomes of APRN's working independently and in collaboration with physicians. Given the increasing number of older-aged persons with chronic diseases expected in years to come, the health care workforce should begin earnestly preparing to meet the needs of this growing and possibly, more demanding population.

Chapter 4: Stakeholder Views of Nursing Home Resident Involvement in Chronic Illness Decision-Making and Self-Management

ABSTRACT

Purpose: To describe the joint perspective of nursing home (NH) stakeholders regarding: (1) opportunities for residents to participate in chronic illness decision-making and self-care and (2) advanced practice registered nurse (APRN) qualities that enhance resident involvement.

Method: A qualitative descriptive method using content analysis was used to analyze secondary data, with the Chronic Care Model as the sensitizing framework.

Results: Thirty-one participants, including 5 residents, 7 family members, 8 APRNs, 5 physicians, and 6 administrators communicated many opportunities for self-management, which were partially limited by a shortage of health care providers and stakeholder disagreement on the purpose of a NH admission.

Conclusions: NH resident participation was perceived as low, despite many, somewhat restricted, opportunities. Greater education and support focused on the purpose of NH admission and attainable self-management goals were seen as necessary steps toward increasing resident involvement in chronic illness self-management.

INTRODUCTION

Over the last two decades, health care has been striving to become more person-centered, allowing the patient to become an equal partner in health care decisions, to improve and enhance health outcomes and satisfaction (Bodenheimer, Wagner & Grumbach, Part 2, 2002; Improving Chronic Illness Care (ICIC), 2012). Some NHs have tried to lead this charge, moving from structured, protocol-driven medical models to more home-like, individualized models of care, where residents may direct their own health care and quality of life outcomes (Koren, 2010). Research into NH resident participation

in health care decisions has been studied from the individual perspectives of residents, families, and health care providers (HCPs) and has often shown that many residents are not participating in health care decision-making and often prefer not to be involved (Bastiaens, Van Royen, Pavlic, Raposo & Baker, 2007; Belcher, Fried, Agostini, & Tinetti, 2006; Wetle, Levkoff, Swikel, & Rosen, 1988). The Baby-boom generation, now reaching older-age and entering into long-term care systems with more chronic illnesses than ever before (Kaye, Harrington, & LaPlante, 2010), promises to be different. This generation is expected to demand a high degree of self-directed, goal-oriented health care (American Hospital Association and First Consulting Group (AHA & FCG), 2007). The U.S. long-term care system is already faced with major problems, including: HCP shortages (Katz, Karuza, Kolassa, & Hutson, 1997; Peterson, Bazemore, Bragg, Xierali, & Warshaw, 2011), escalating health care costs (Calmus, 2013; Mettler & Kemper, 2007), and major federal budget cuts (The Alliance for Quality Nursing Home Care, 2012). This additional demand by NH residents in the very near future prompted the need to describe the opportunities currently available for residents to participate in their health care decisions, and to explore how resident participation can be enhanced. This study described these opportunities for resident involvement from the joint perspective of NH stakeholders as a whole, including HCPs, administrators, residents, and family members.

BACKGROUND

NH population

The current long-term care population, including home-bound, assisted living, and NH residents, numbers approximately 12 million people and is expected to more than double to 27 million by 2050 (Kaye et al., 2010). People are living longer due to healthier lifestyles (AHA & FCG, 2007). However, not dying from acute illnesses has translated

into living longer with chronic illnesses and the disability and expense that accompany them. Chronic illnesses currently faced by NH residents in the U.S. include: hypertension (68%), depression (45%), dementia (39%), diabetes (31%), arthritis (24%), chronic lung disease (19%), heart failure (19%), and stroke (16%) (Centers for Medicare and Medicaid Services, 2012). Current NH residents, from a generation commonly known as the "Silent Generation" or the "Veterans," born between 1922 and 1945, lived through WWII, the Korean War, the Great Depression, and racial segregation, experiences that are thought to have contributed to their known core values of loyalty, sacrifice, hard work, and respect for authority (University of Iowa, 2009). In health care situations, they tend to respect the authority and expertise of HCPs with little question. They may not complain if unhappy, and they may not concern themselves with decisions unless asked to do so (Thornton, 2009).

In direct contrast to this philosophy is the philosophy of the up-and-coming older generation known as the "Baby-boomers." Boomers in general, have primarily lived through economic prosperity and the fight for Black civil rights and women's civil rights. Their lives have generally allowed for higher education, wealth accumulation, and self-exploration. As a group, they tend to value youth, health, and money (University of Iowa, 2009). Because close to 90% of boomers are high school graduates and almost 60% have attended college (U.S. Census Bureau, 2006), they commonly use technological expertise, social networking, and the web to independently obtain and evaluate health information. It is expected they will remain active and in control longer, desiring health care focused on mobility and independence, and medical care that meets high standards, and is individualized, innovative, and holistic (American Association of Retired Persons (AARP), 2011; AHA & FCG, 2007).

Resident involvement in health care decision-making

Desire for involvement in health care decision-making and self-care by NH residents is quite heterogeneous and requires HCPs to be diligent in assessing, understanding, and responding to these preferences (Wetle et al., 1988). Often, admission into a long-term care setting is prompted by an inability of the patient to independently manage the complications and disability brought on by later stages of chronic illnesses (Gaugler, Duval, Anderson, & Kane, 2007). Residents may be overwhelmed with the stressors of illness and leaving their homes and families, and may slowly relinquish their right to take part in health care decisions (Shawler, Rowles, & High, 2001). Consequently, family members, as well as HCPs and administrators, often have a high level of involvement in health care decision-making that tends to increase over time as resident health declines (High & Rowles, 1995; Shawler et al., 2001). However, there are also cognitively and physically capable NH residents who choose not to participate in medical decision-making. Funk (2004) found that an average of 27% of 100 cognitively intact long-term care residents preferred to relinquish all or most decision-making control to others, while Wetle et al. (1988) reported that 53.7% of their cognitively and physically capable sample wanted little or no involvement in medical decisions. Some may not participate because they place implicit trust in HCPs while others may be uncomfortable with questioning HCPs (Waterworth & Luker, 1990). Thus, there are clearly factors other than cognitive or physical capability that may play a role in preference for non-participation in this setting.

Indicators of greater participation or involvement in health care decision-making by patients include: younger age (Bastiaens et al., 2007; Benbassat et al., 1998; Wetle et al., 1988); higher education (Benbassat, et al., 1998; Thompson, Pitts, & Schwankovsky, 1993); and greater confidence in making a difference in decisions made (Ashworth,

Longmate, & Morrison, 1992; Belcher et al., 2006; Funk, 2004). Beneficent paternalism on the part of HCPs in an effort to promote patient safety and control health outcomes has been qualitatively interpreted as a barrier to NH resident participation in decision-making (Hughes & Goldie, 2009; Shawler et al., 2001). Belcher et al. (2006) and Schulman-Green, Naik, Bradley, McCorkle, and Bogardus (2006) suggested that a lack of quality time spent with older-aged patients by HCPs may decrease patient decisional involvement.

Qualitative researchers (Bastiaens et al., 2007; Schoot, Proot, ter Meulen, & de Witte, 2005) have proposed there may be relationships between older-aged persons' decisional and self-care involvement and level of self-confidence, autonomy, validation of personhood, and individuality. Others (Schoot et al., 2005; Shawler et al., 2001) have suggested that non-involvement by those who desire involvement may contribute to feelings of frustration, anger, isolation, and inferiority. Encouraging individuals who have no desire for involvement may also be stressful or viewed as unethical (Rodin, 1986; Waterworth, & Luker, 1990). Therefore, it is important not only to investigate whether a resident prefers involvement and to what degree they prefer to be involved, but also to explore possible reasons for these choices, in order to ensure maximum opportunities for involvement are provided without undue pressure to participate.

NH stakeholders

HCPs in the NH, including nurse assistants, staff nurses, APRNs, physicians and physician assistants, as well as family members and administrators, can be key to a resident's sense of self, home, control, and overall quality of life (Tester, Hubbard, Downs, MacDonald, & Murphy, 2004). HCPs in this setting have several competing obligations. They must meet high and specialized standards of medical care for older-

aged persons while ensuring that care is person-centered, meets federal and state regulations for quality and payment, and allows for resident and family personal space and autonomy (Welford, Murphy, Wallace & Casey, 2010). In addition, a shortage of HCPs, increased patient acuity, expected increases in census, and current and expected decreases in federal and state funding, place added pressure on the long-term care health system to provide high quality, affordable care (Raphael, 2003). Residents receiving care must also attempt to balance accepting necessary losses of independence (Rodin, 1986), while family members often deal with feelings of guilt and sadness (Ryan & Scullion, 2000), making participation in medical and daily life decisions more difficult. Thus, there are several complex and varied emotions, goals, and interests among NH stakeholders. Each may be directly influenced by the perceptions and actions of the others.

The APRN is uniquely positioned to aid in the provision of high quality medical and nursing care in the long-term care setting. APRNs include nurse practitioners and clinical nurse specialists, holding masters or doctoral degrees in nursing. Many have additional certification in gerontology and multiple years of nursing clinical experience and are capable of providing comprehensive chronic illness and primary care and/or consultative services including some form of prescriptive authority (Rosenfeld, Kobayashi, Barber, & Mezey, 2004). Nurse practitioners have been found to provide equivalent or better care of chronic illnesses than provided by physicians (Aigner, Drew, & Phipps, 2004; Brown & Grimes, 1995). They have been found to lower rates of hospitalization (Burl, Bonner, & Rao, 1994; Garrard et al., 1990; Intrator, Zinn, & Mor, 2004; Joseph & Boult, 1998) and provide more holistic care to older-aged residents of NHs, focused on the preservation of dignity and autonomy (Abdallah, 2005; Kappas-Larson, 2008). APRNs often work collaboratively with physicians in long-term care, and unlike physicians who have reported being able to spend only about 4% of their work

time in NHs (Katz et al., 1997), APRNs generally spend the majority of their work day in the long-term care setting, extending resident, family, staff, and facility time spent with the medical HCP, improving quality of care and patient satisfaction (Bakerjian, 2008). The ability to alleviate the shortage of gerontological medical HCPs with the type of person-centered care that makes up the philosophy of nursing and that has been found to be missing in current long-term care, prompted us to explore further how the APRN can enhance opportunities for resident participation in chronic illness decision-making and self-care.

Study purpose

The primary aim of this study was to provide a balanced description of NH resident participation in health care decision-making and self-care and its influencing factors from the perspective of several key NH stakeholders. A secondary aim was to explore how the APRN may enhance opportunities for resident health care decisional and self-care involvement in this setting.

METHODS

Pilot work

To investigate the feasibility of conducting qualitative work examining NH resident preferences for involvement in their treatment regimens, we conducted an ethnographic pilot study, sampling 3 residents with type 2 diabetes, an exemplar chronic illness (Garcia & Harrison, poster presentation, 2012). Over a period of 3 months, one audiotaped interview and 3 participant observation visits were conducted per participant. Domain analysis and explanatory modeling yielded themes suggesting that residents had definite preferences for their diabetes plans of care but were unaware their preferences could impact their treatment. Methods from this study verified the feasibility of gaining

access into NHs for qualitative research and findings supported the need to further investigate the perceptions of NH residents regarding their chronic illness plans of care as well as the perspectives of other NH stakeholders.

Data source and sample

The present study is a secondary analysis of qualitative work conducted by Harrison, Garcia, Goodwin, and Kuo (2012), sampling 31 NH stakeholders across 11 Texas NHs, regarding medical management choices in the NH, specifically focused on HCP selection, with an emphasis on organizational quality and patient-centered care. The focus of this secondary analysis was on resident opportunities for involvement in chronic illness decisions and self-care, viewing the data through the lens of the Chronic Care Model (ICIC, 2012). Both the parent and secondary analysis studies sought to obtain the joint perspective of NH stakeholders as a whole in order to encompass their many viewpoints into one complete and balanced description of the phenomena (Milne & Oberle, 2005; Morse & Field, 1995).

Types of stakeholders interviewed included: NH residents, family members of residents, APRNs, physicians, and administrators. Residents were eligible for participation if they were age 60 or above, spoke and understood English, were able to provide independent informed consent for research and medical treatment per facility policies, and had resided in a NH for at least 3 months. Family members had to be related to a NH resident aged 60 years or older, living in a NH for at least 3 months. APRNs and physicians had to be current HCPs of medical care to NH residents. Administrators had to have at least one year of experience in an administrative role in a NH setting. After Institutional Review Board approval from The University of Texas at Austin, recruitment of participants was conducted through purposive sampling. Semi-structured audiotaped

interviews lasting approximately one hour were conducted, including self-report of demographic characteristics. Resulting de-identified interview transcripts, previously checked for accuracy, and demographic data via SPSS version 20, were used for this analysis.

Design and sensitizing framework

A qualitative descriptive design was used to conduct the study. Selected concepts of the Chronic Care Model (ICIC, 2012) including health systems (administrator and facility), self-management support, decision support, patient (resident and family), practice team (physician and APRN), and productive interactions (between practice team and resident/family), were used as a lens through which to view the data as well as to frame the research questions and secondary analysis. (See Table 7.)

Data analysis

Qualitative content analysis, integrating both deductive (from the Chronic Care Model) and inductive (from the data) analyses, was used to generate categories and subcategories that provided an emic description of NH resident involvement in chronic illness care decisions as viewed through the lens of the Chronic Care Model. An initial coding frame was devised based on key aspects of each research aim (major categories) and subcategories were derived deductively from the conceptual framework as well as inductively from the data (Schreier, 2012). During a pilot coding phase of two interviews from each participant type, categories were renamed using participants' actual words and new categories were added in the interest of developing a coding scheme that stayed as close to the surface of the data as possible but allowed for the emergence of new ideas across categories (Sandelowski, 2000).

Subcategories were collapsed into larger categories until a final modified coding frame was completed and all remaining interviews were coded (Saldana, 2009; Mayring, 2000). Previously coded interviews were re-coded to check for coding consistency and to ensure all interviews were coded using the complete coding frame (Schreier, 2012). Analytic memos were kept on the coding worksheet to record reasons for coding and categorizing decisions. A separate analytic journal was also used to record first impressions and later interpretations of overall interviews. Exemplars of participant quotes for each category and subcategory were identified from the data to ensure the analysis stayed close to the words of the participants (Morse & Field, 1995). Participant demographics were used to add context to the descriptions. Study trustworthiness was achieved through the involvement of the researchers in collection of the original data, re-coding to ensure coding consistency, and audit trail.

RESULTS

Thirty-one NH stakeholders were interviewed (see Table 8) including: 5 residents with mean length of stay 34 months who reported 3 or more chronic illnesses each and being cared for by both a physician and APRN; 60% reporting “feeling closest” to the APRN; 7 family members; 5 physicians, of whom 1 reported a specialty in gerontology and none reported NHs as their sole practice; 8 APRNs, of whom 4 reported a specialty in gerontology and 4, a sole practice in NHs; and 6 NH administrators.

Analyses revealed overall themes of stakeholder non-commitment to resident participation in chronic illness management and a lack of agreement on the purpose and goals of the NH admission. Although there were opportunities for residents and families to make health care decisions and to be involved in self-care activities, they were perceived by stakeholders to be limited, inadequately supported, or misunderstood.

Several stakeholder qualities, such as residents' level of cognitive impairment or illness severity or APRNs' ability to recognize the resident as an individual, were described as facilitators or barriers to involvement. The data suggested that because so few residents were perceived to be capable and/or interested in participating in health care decision-making or self-care activities, the basic elements of successful self-care management as outlined by the Chronic Care Model were not supported in the nursing home setting.

Categorical findings

Opportunities for decision-making and self-care activities

Several opportunities for resident involvement in health care decision-making were discussed by the stakeholders such as the ability to choose what hospital to be transferred to, which pharmacy to use, which physical therapy company to use, or whether to be transferred to another room, to a hospital, or into hospice care (see Table 9). Opportunities to take part in self-care were also plentiful, including: exercise method, physical therapy frequency or duration, dietary menu, meal times, type and timing of medications; and when to see a medical HCP. However, within many of these discussions of choices, there were well-recognized caveats or limitations, often imposed by lack of financial resources or regulatory restrictions.

> They can opt either to pick one of the people [pharmacies] that we work with or go to their pharmacy and ask them to comply with this [regulations] (Admin-2).

> There are times when I'd like physical therapy for my patients but they are not eligible because they've had too many days on a calendar year. So, you know, Medicare can get in the way… (APRN-6).

The data were filled with opportunities for residents to take part in decisions regarding their care plans and their self-care activities; however, all stakeholders

mentioned one or more limitations to most of these choices that seemed to diminish the power or importance of the choice.

Decision support

Decisional support provides the resident and family with chronic illness education and information needed to make informed decisions, such as evidence-based guidelines for care and how those guidelines can be individualized. There were several opportunities for productive interactions between HCPs and facilities where chronic illness care information and choices could be explained and explored with residents. There was no mention of sharing evidence-based guidelines or exceptions to those guidelines in these data. Modes of communication included: care plan meetings, initial admission meetings, HCP visits, problem-prompted meetings or phone calls requested by HCPs or family members, social worker visits, and resident council meetings. Stakeholders had widely varying perceptions of the purpose, frequency, and need to attend the care plan meeting For example, some described it as a forum to discuss the resident's condition and plan of care, others thought it was more for administrative concerns, while others thought it was primarily for residents to voice their facility-related complaints. Initial admission meetings were generally described as meetings that took place within 72 hours of admission where the resident and family members were informed of facility routines, their preferences were requested, and goals were discussed. Interestingly, none of the resident or family member participants mentioned this meeting and mention by other participants varied in description of purpose. Some described the admission meeting as a discussion of resident goals and preferences while others described a discussion of reasonable goals based on realistic expectations.

> We meet very often with patients and their families to try and make sure that we've answered questions and addressed the expectations of their goals. And then

> try to revise the goals so that those goals are reasonable and obtainable within the resources, both time wise and medically, that are available (Phys-5).

Physician visits were described as being primarily problem-oriented. APRN visits were described as being lengthier, more routine, and a friendlier arena to discuss chronic problems, concerns, fears, goals, and plans.

> And as far as the personalities, [the APRN] is a more … talkative type person, and she just would—if nothing else involved, you might select that one above the other ones. [The Physician] is more of strictly business. The other one is more conversant (Res-3).

> To do rehab, to really get going on that, I think she [APRN] was really responsible for that. And it was because I wanted to be able to stand, at least…. I'm really thrilled. This is almost like a miracle ...I was able to push myself up from the chair...try to stand up straight.... and actually take a little bit of a step forward, yeah. (Res-4).

There were several opportunities to provide decisional support to residents and families but stakeholders described differing ideas of the purpose and need to attend these meetings.

Self-management support

Opportunities for self-management support were realized through much the same avenues as discussed above, i.e. care plan meetings and HCP visits. Self-management support includes providing encouragement and support to the resident and family, empowering them to feel they are important to the care planning process: "What I always like to tell people is that I want to be partners in their health care and … I don't want this to be just my decision… (APRN-8).

Educating residents and families regarding chronic illness treatment choices, and encouraging them to participate through questioning, listening, and following through with requests and preferences were described: "…lots of times, you'll explain something to them and they're like, 'nobody ever explained that to me that way'" (APRN-6).

However, stakeholders recognized the difficulty in supporting self-care management in this setting:

> Sometimes we get so bogged down in the task and the institutionalization and the rules and all of this that we forget that we're dealing with people and that they have choices and that sometimes their choices don't mesh with what the medical community believes is in their best interest. And we need to ask them, "what do you all want?" (Admin-2).

Stakeholders described instances of missing or inadequate support, especially with regard to dealing with overwhelming problems related to NH admission such as financing issues, insurance questions, social losses, and illness severity.

> My main support would be myself and my sister. … When you don't know anything about it … it's just overwhelming for someone that doesn't know or understand the system…. just overwhelming, heartbreaking. (Fam-2).

There was no mention of any type of formal resident or family support groups within the NH to help with NH admission processes and changes or to provide late stage chronic illness care education. Again, there were opportunities to provide support for resident involvement but they were not perceived as effective or adequate by stakeholders as a whole.

Factors affecting chronic illness care involvement

The data provided insights into qualities, characteristics, and actions of or by particular stakeholder groups perceived to either help or hinder the ability of residents to be involved in decisions or in their care regimen activities. Overall, stakeholders perceived cognitively capable residents to be more likely to participate in their health care if they were: healthier, more mobile, happy, vocal, of higher socioeconomic status, confident in their knowledge about health care issues; and had involved family. Family members were felt to be more likely to participate and support the participation of residents if they were educated, informed, knew the resident's health issues, and visited

frequently. Conflicting responsibilities from job and family that prevented frequent visiting and implicit trust in HCPs or fear of displeasing HCPs were seen as inhibiting factors to family involvement.

HCPs were perceived to facilitate resident involvement by being easily available to residents and staff, spending time with and knowing the residents as individuals, having a friendly demeanor, and being willing to place resident preferences above protocol, age bias, and keeping control of outcomes. The NH system's economic goals of keeping census as high as possible, fee for service payment, and disorganization of records were seen as contributors to lack of HCP time with residents. High governmental regulation and insurance restrictions were associated with lack of resident choices in daily living and chronic illness treatment activities.

APRN qualities perceived to enhance resident involvement

Stakeholders described APRNs as being highly visible and vital to the smooth, cost-effective, quality operation of a NH facility. They were consistently seen as the key to resident involvement or participation in medical care decisions and treatments. APRN qualities included: valuing each resident as an individual; spending the time necessary for explanations of conditions and treatment options, resident questions, concerns, and opinions or decisions; providing compassionate, innovative, holistic care; and collaborating with NH staff providing leadership, education, and high accessibility to medical expertise.

Stakeholders described other APRN qualities that were not directly related to resident involvement, including: being an expert in gerontological nursing and medicine; preventing avoidable decline and hospitalization; providing time efficient care to as many patients as possible; and meeting the regulatory and economic needs of the facility and

the physician practice. Some of these latter expectations appeared to conflict with the provision of resident-directed, holistic care. The APRN was expected to spend more time with residents and staff as well as to see as many patients as possible to satisfy the nursing facility's regulatory needs and the physicians' practice economic needs.

Perceptions of resident/family desire for involvement

Stakeholders, as a whole, even some of the residents, perceived that few residents (some estimated between 5-15%) desired involvement in their health care management. All participants agreed that involvement of residents was most dependent on their cognitive abilities, although education level, general outlook, confidence in medical knowledge, and degree of family involvement were also mentioned as determinants. Stakeholders perceived that most family members had some involvement in health care decisions, although several spoke of increasing family non-involvement:

> It's a little sad on that. I'm seeing more and more, as years go by, less and less family involvement. It's getting more where this is kind of a—just a drop them off and, you know, I might see you in a couple of months type thing (Admin-4).

Several stakeholders discussed extremes of family involvement, describing families who were completely uninvolved and never visited or only visited once or twice a year, and families who visited daily, and had "unrealistic" demands of staff and HCPs. Stakeholders felt the motivation for lack of visitation or unrealistic demands might be due to guilt feelings, although some felt family members lacked the time due to other family and job demands, or just trusted HCPs and the health care system to do their jobs well.

Thematic findings

Perceived prevalence of non-commitment or disinterest

There was an overall theme of non-commitment to resident involvement in the plan of care and in self-care activities that emerged from this data. Stakeholders

perceived a great majority of residents to be either incapable or uninterested in participating in the chronic illness plan of care. They described limited choices and inadequate opportunities provided by the NH system to support and engage the resident in care plan decision-making and self-care activities, sometimes due to federal regulations and/or contractual agreements with external agencies, such as pharmaceutical vendors. They felt that although most family members were involved in the plan of care, there was a trend toward less involvement and/or ineffective over-involvement. HCPs were described as stretched too thin to spend the time necessary to support residents, family, and staff in the provision of resident-directed care. Thus, although stakeholders appeared to recognize the importance of providing residents with choices regarding their care, they did not expect most residents to be involved and did not feel that others within the system were working together to support involvement.

"Reasonable and attainable" goals

The second underlying theme emerging from this data was the lack of agreement or consensus on the purpose of the NH admission and on attainable goals. Almost all residents communicated either directly or indirectly the overall goal to return home: "…but if they offered me a million dollars to stay here for the rest of my life, I would say, 'no; say, keep your million dollars. Let me go home'" (Res-1). For most long-term care residents, who were the subject of this research, returning home was not a likely option. Stakeholders described the goals of under-involved or over-involved family members as being unrealistic at times. They often expected the resident's condition to improve or remain stable, again, a generally unreasonable goal in the case of late stage chronic illness. Health care providers and administrators expressed the desire to provide person-centered, individualized, high quality medical care while seeing as many patients

as possible in a given period of time with limited financial and professional resources. These sometimes conflicting and often disagreed upon ideas of purpose, expectations, and goals of stakeholders provided a seemingly unlikely environment for the provision of person-centered or resident-directed care.

View through the lens of the Chronic Care Model

Why are most NH residents not involved in their health care? These data suggest that the pursuit of goals that either conflict with or are not agreed upon by stakeholders may be preventing true progress toward resident self-management, despite best efforts by all. The Chronic Care Model stresses the importance of four major elements of successful self-management programs: (1) team (including the patient) definition of problem; (2) realistic, personalized, goal-setting; (3) continuous self-management support and education; and (4) effective and sustained follow-up (Wagner, Austin, & Von Korff, 1996). These critical self-management elements were not evident in these data, perhaps because residents were not expected to self-manage. The basic definition of the problem for residents or the purpose for NH admission was not seen as an agreed upon concept among these stakeholders. From these data, we inferred that many felt a NH was a place to get well enough to return home; while others believed it was a place to be kept as healthy as medically and economically possible. These, as well as the rather improbable goals described above, are examples of a sort of NH enigma, conflicting ideas of purpose, expectations, and goals, which until resolved, may make true resident-directed care, and other principles of person-centered care in a NH difficult to achieve.

Figure 4 presents proposed modifications to the Chronic Care Model for the NH that incorporate the findings of this study focused on the key elements for successful chronic illness self-management as described by Wagner et al. (1996). This modified

model tentatively proposes sub-categories (bulleted items) under each of the original CCM studied concepts (outlined in orange) that are specific to the nursing home setting, as well as additional concepts and areas of focus (outlined in red), interpreted from these data as important to the involvement of residents in self-care management. The modified model suggests the need to quantitatively test relationships among the new concepts and existing concepts, and the health and quality of life outcomes of nursing home residents. Proposed changes or increased focus in the modified model include: continuous support groups to help define the problem or purpose of the nursing home admission; effective care plan meetings to facilitate productive interactions; quality interactions between resident/family and providers to improve agreed upon, attainable goals; and follow-up and readjustment of goals as needed, to promote health and quality of life outcomes congruent with resident preferences.

DISCUSSION

NH stakeholders described several opportunities for residents and family to participate in chronic illness care decisions and self-care activities, but there were caveats to almost every available resident choice; residents were "making decisions based on just what's there" (APRN-1) The limitations implied a degree of non-commitment on the part of NH facilities and/or HCPs. For example, the ability to choose a meal but having only one alternative implied a facility shortcoming, possibly due to lack of financial resources. Problems with these types of limitations could lead to disinterest in making choices or other health-related problems. Burger, Kayser-Jones, and Bell (2000) found that lack of sufficient or appropriate food or menu choices was a contributor to widespread malnutrition and dehydration in the long-term care setting.

Opportunities to provide decisional and self-management support to the resident were clearly available in the form of care plan meetings, admission meetings, and HCP visits, but again, there were limitations. The greatest seemed to be the inconsistent format of the care plan meeting and the absence of residents and inconsistent presence of medical HCPs at these meetings. Although, this type of meeting seems the perfect venue for promotion of involvement and productive interactions between residents and HCPs and is required by federal NH regulations, attendance by these stakeholders was perceived as rare or at most, very inconsistent. The National Senior Citizens Law Center listed care planning as the second most common problem in NHs today in that residents and families do not understand they have a right to ensure that care plans center on the resident's needs and preferences (Carlson, 2010).

The perception of disinterest continued when describing whether residents and families were perceived to be involved in health care decisions or self-care activities. Only a small percentage of residents were perceived by stakeholders as involved or interested in their health care decisions and self-care activities, due to cognitive incapability, illness, depression, lower education, or generational background. However, all residents sampled and several other stakeholders felt that definitely some residents were very interested in decision-making and self-care activities. Most family members were perceived as involved to some extent, although there was discussion of a trend toward less involvement or over-involvement. Some family members discussed the NH admission experience as "overwhelming, heartbreaking." There was no mention of available support groups for residents/families to assist with education and counseling regarding changes associated with NH admission, long-term stay, and chronic illness course and treatment options. The use of support groups for NH residents and their families has been encouraged to help them understand role changes and cope with new

stressors (Bern-Klug, 2008; Campbell, 1996). Maas et al., (2004) found that educational sessions with families of dementia patients helped improve families' experiences and staff attitudes toward family members.

Physicians were described as being less available, in a hurry, and more business-like than APRNs who were perceived to have more time to spend with residents, families, and staff. Several other studies incorporating the perceptions of patients and NH residents also found that physicians were seen as unconcerned or having poor interpersonal skills (Bastiaens et al., 2007; Belcher et al., 2006; Schulman-Green et al., 2006; Walent & Kayser-Jones, 2008). Stakeholders listed many APRN qualities that enhanced resident involvement, however, despite the application of these qualities, decisional and self-care involvement of cognitively capable residents was still perceived to be very low. Additional APRN qualities, more focused on meeting the expectations and needs of the facility and physician practice, were also listed as necessary, including the need to see as many patients as possible. This necessary characteristic seemed to conflict with the involvement enhancing qualities, possibly explaining in part why APRNs in this setting may not be making a large difference in resident involvement.

Seeing as many as patients as possible in the time given is necessary not only for a financially successful practice but also to ensure that all residents are seen in a timely manner. It appears then that an underlying problem to resident involvement may be the continued shortage of HCPs in this arena. Thus, although it may appear as though there is disinterest or non-commitment by HCPs due to their rush and hurry demeanor, it is much more likely that these individuals are interested and committed but there are just not enough of them. The need to increase the number of HCPs in this setting has been reiterated by many (Eldercare Workforce Alliance, 2013; Institute of Medicine (IOM), 2008; The American Geriatrics Society, 2012), and although APRNs are providing badly

needed coverage, their numbers are also low and obstacles such as limited scope of practice in the NH setting may contribute to the problem (Bakerjian & Harrington, 2012; IOM, 2011).

These data also provided insight into stakeholders' goals for resident outcomes and their perceptions of the purpose of NH admission in this setting. Most residents, during the course of their interview referred to the underlying desire to get better and go home. Never going home would then mean never attaining goals. It may be that some residents are not interested in participating in their care because they are continuously disappointed in their achievements and see no point in pursuing them. Support not only to explore goals and preferences but to support and encourage movement toward achievable goals that can be realized and bring satisfaction is indicated.

Similarly, the goals of the over-involved family members were described as "unrealistic" or "overly optimistic," such that family members had goals for resident health status to improve or remain static, which with end-stage chronic illness is rarely the case. This, again, is an indication for family support groups and education regarding the course of chronic illness, goal-setting, and the purpose of a NH admission. Perhaps if this support and information were offered prior to NH admission, in the general public arena, fewer family members would experience the guilt frequently mentioned by stakeholders and associated with the perception of abandonment of the resident in the NH.

Stakeholders described HCP goals as: wanting to spend more time with residents but also to see as many residents as possible and to provide high quality medical care with high quality medical outcomes using minimal medication, fewer hospitalizations, less money, and few HCPs. These are extremely difficult goals. Similarly, stakeholders perceived facility goals as providing safe, high quality individualized, autonomous care

within a highly regulated environment with minimal economic and personnel resources. These goals, although admirable, again seem quite difficult to attain. There appears to be a clear need for stakeholders to come to some agreement as to the purpose and focus of care provided in the NH setting, and to set attainable goals to fulfill this purpose.

Use of the Chronic Care Model as a lens through which to view these data revealed a lack of the basic elements proposed by Wagner et al. (1998) necessary for successful self-management (team agreement on purpose and goals, attainable goals, and continuous evaluation of goals). Because stakeholders expressed low expectations for successful resident self-management to occur, it was not surprising that the elements necessary for self-care success were missing from these data. These low expectations for resident involvement were also found by Funk (2004) who questioned why there was this assumption among long-term care stakeholders that autonomy somehow is of less importance or relevance in this setting. Quantitative research focused on the relationship between stakeholders' expectations for resident involvement, actual resident involvement, and outcomes of involvement, is necessary to determine how influential stakeholders' expectations are on the provision of person-centered care.

IMPLICATIONS

Stakeholders in NHs should understand and agree upon the purpose of a NH for older-aged adults with late-stage, chronic illnesses. Support groups for potential and current NH residents and families both inside and outside the NH facility could focus on this understanding and prepare families and residents for the many changes associated with NH admission. A large scale media push, perhaps headed by organizations such as AARP or The National Consumer Voice for Quality Long-Term Care, to educate the

general public on the purpose, benefits, and goals of NHs would be beneficial in reducing the guilt, fear, and dread often associated with NH admissions. Positive publicity might also improve the public image of NHs, attracting more HCPs and increasing taxpayer and health insurance support. Additional, easily accessible support groups on specific chronic diseases, goal-setting, available treatment options, and expected health outcomes could enhance resident/family participation in health care decision-making and self-care activities. Education for health care staff and medical HCPs on these same topics is also necessary. Additionally, a well-defined, well-attended care plan meeting is essential to maximize communication and resident-directed care.

The support necessary for resident-directed care in NHs is not likely to materialize or be sustained without changes in health care policy. Changes suggested by this study include: mandating and financing the education of all stakeholders and the general public on the purpose and goals of NH admission and the importance of teamwork and effective communication; passing legislation to alleviate the HCP shortage, e.g., allowing APRNs to practice to the full extent of their educational preparation in all states; and revising federal and state NH regulations that may present barriers to the provision of resident-directed care.

LIMITATIONS

The limitations of secondary analyses apply here including possible lack of data saturation due to the inability to continue sampling and the inability to tailor questions based on ongoing analytic findings (Whittemore, Chase, & Mandle, 2001). However, the researchers did feel saturation was reached in that all available transcripts yielded similar concepts, which fell into existing categories (Schreiner, 2012). A possible gap was the missing voice of NH front-line caregivers, staff nurses and CNAs. Future studies should

include this vital section of the health care team to obtain perhaps a deeper understanding of NH resident involvement in chronic illness care.

CONCLUSIONS

Stakeholders agreed that few NH residents are interested in health care regimen involvement and decision-making. Given the aging Baby-boom population and their ideals, these numbers are likely to increase. NHs offer several opportunities for chronically ill residents and their families to take part in care planning and treatment regimens but they are laden with limitations. APRNs exhibit qualities that currently increase the presence of medical HCPs in the NH and improve resident comfort and willingness to participate in their health care; needs that promise to grow rapidly in coming years. However, a continued shortage of medical HCPs and conflicting stakeholder ideas of purpose and goals of NH admission were interpreted as barriers to resident and family involvement. Pre-nursing home admission, and in-facility education and peer/provider formal support for all stakeholders was suggested to improve the involvement of residents and their families in chronic illness care decisions and self-care management. An intervention study to investigate the effects of additional resident/family support and education on resident and family quality of life outcomes and the alignment of outcomes with resident preferences is needed. Additionally, the examination of resident outcomes and their congruence with resident preferences under different models of care, testing different roles played by nurse practitioners, clinical nurse specialists, physician assistants, and physicians, will shed light on ideal chronic illness management models for nursing homes.

Chapter 5: Summary of Work

PURPOSE AND SIGNIFICANCE

The purpose of this dissertation was to describe the management of chronic illness in older-aged adults residing in the nursing home setting with an emphasis on the involvement of the resident in chronic care-related decisions and self-care activities and how that involvement may be enhanced. The Baby-boom generation, now beginning to surpass age 65, is expected to enter older age burdened with chronic illnesses but enlightened by higher education, technological expertise, and a zest for personal control and autonomy. Like all before them, this generation will likely resist nursing home admission for as long as possible. But unlike others, if and when they do require a nursing home stay, they are likely to be quite demanding of person-centered, innovative, individualized care. Nursing homes have struggled to provide high quality medical and nursing care while maintaining a home-like environment, a difficult goal for any health care entity, but especially for one also struggling with a shortage of qualified personnel and inadequate funding. This study endeavored to describe current practices of chronic illness management in nursing homes, the opportunities available for resident-directed care, the factors that influence those opportunities, and how person-centered, resident-directed care can be enhanced in the near future (especially through the APRN) for the benefit of the nursing home system and its current and future residents. Wagner's Chronic Care Model served as the lens through which all data were viewed and helped to frame research questions, analytic findings, and conclusions. Four research projects were undertaken to accomplish these goals.

Three overall research aims were chosen to accomplish the above objectives: (1) to describe the extant quantitative research on the management of an exemplar chronic illness, type 2 diabetes, in the nursing home; (2) to describe, through meta-synthesis, the

qualitative research exploring the involvement of chronically ill older-aged adults in everyday decisions surrounding their chronic illness care regimens; and (3) to describe, from the joint perspective of nursing home stakeholders, the opportunities available to older-aged nursing home residents to participate in decision-making and self-care activities and to explore how these opportunities can be enhanced.

SUMMARY OF FINDINGS

The first project answered **Research Question 1** under **Aim 1**: *What are the current type 2 diabetes management practices in the nursing home setting?* This study was a systematic review of the literature that encompassed the review of 523 articles gleaned from a systematic search of ten medical and psychological databases. Diabetes was chosen as the exemplar chronic illness because more than 30% of older adults in nursing homes are diagnosed with diabetes (CMS, 2012), and slightly less than 30% of adults 20 to 79 years have undiagnosed diabetes (International Diabetes Federation, 2011). Even greater percentages suffer from the complications of diabetes including hypertension, heart disease and heart failure, renal failure, amputation, stroke, depression, and dementia. The study addressed the characteristics of diabetes management practices, whether clinical practice guidelines were used to guide diabetes management, and the effects of different management regimens on resident outcomes.

Twenty descriptive studies, including a total sample of 65,029 residents, met criteria and were critically analyzed. The findings included frequent low adherence to current clinical practice guidelines for the management of type 2 diabetes in nursing homes. For example, 40% of residents in this sample were not being treated with any diabetes medications, 54.2% were being administered insulin doses based on a routine sliding scale, and 72.4% were on restricted diets, practices not consistent with current

guidelines. It was unclear as to whether there was actually a lack of evidence-based practice or if there was more a lack of documentation that guidelines had been considered but relaxed or modified based on individualization of care. A significant gap in the literature describing the relationship between different diabetes management practices and resident outcomes was found. It was also noted that the perspectives of the resident and family were absent in the management practices described. Some studies did interview residents but the data were analyzed for content only and studies were not qualitative in nature. Under the lens of the Chronic Care Model, it was clear that more work was needed to determine whether decisional and self-management support were being provided to the resident, informing them of evidence-based guidelines, providing them with options as to management regimens, and encouraging their involvement through the provision of more formalized support groups.

The second project answered **Research Question 2** under **Aim 2**. This study was a metasynthesis of the qualitative literature addressing the following research questions: (a) *What does involvement in daily chronic illness care decision-making mean to older aged patients?* and (b) *What factors hinder or improve their involvement in decision-making?* The authors originally set out to describe the older-aged person's point of view on chronic illness management in the nursing home. Because there were too few studies done in nursing homes, the sample was enlarged to include older-aged patients with chronic illness living in the community. Thus, a meta-synthesis of the qualitative literature on the involvement of older-aged community or nursing home-dwelling patients in chronic illness decision-making was conducted. A search of 5 health-related databases yielded 1020 articles which were reduced to 7 studies (sample size of 541) after reviews for inclusion criteria and quality appraisal. Domain and comparative analysis techniques yielded 4 major themes across studies: (1) *Being recognized because I matter*; (2)

Awareness of importance; (3) *Empower through connections and opportunities*; and (4) *Time is precious.*

Being involved or included in chronic illness decisions was described by patients as being recognized as a person of importance, worthy of being listened to and consulted. Being left out of these decisions was described as communicating feelings of inferiority, isolation, and powerlessness. Patients perceived barriers to involvement in decision-making as physical frailties, forgetfulness, implicit trust in health care providers, and most of all, little time spent and poor communication by health care providers that left the impression of disinterest or unimportance. They expressed facilitators of involvement as including better informing themselves of health care issues through books, magazines or the internet, being provided with detailed explanation of illnesses and options, and being encouraged to participate by health care providers. The nursing home studies focused most on barriers to involvement of residents, namely, beneficent paternalism. Health care providers were described as unwilling to give up control over health outcomes to resident preferences that might not result in the "best" outcomes. Nursing home and community studies stressed the need for health care providers to empower patients to become involved through compassionate and patient communication.

An overarching theme, threaded through all the studies was the concept of time being a very precious commodity. Patients expressed that time spent with them communicated caring, compassion, and relevance. Because research has shown that APRN's spend more time with patients than physicians and can provide equal if not better primary and chronic illness care, the study discussed the implications for these nurses to enhance patient decision-making involvement in gerontological practice. The Chronic Care Model emphasizes productive interactions between health care providers and patients to facilitate patient-centered outcomes. This study delineated specific

characteristics of providers and patients that hinder or enhance these interactions and may make the difference between a patient experiencing older age of the quality he/she desires or of the quality seen as ideal by health care providers.

The third and fourth projects addressed **Research Question 3** under **Aim 3**: (a) *What are the opportunities for nursing home residents to be involved in making decisions regarding their chronic illness plans of care?* (b) *What are the opportunities for residents to be actively involved in self-care activities within their chronic illness health regimens?* and (c) *What qualities do APRNs possess or need to possess to enhance residents' involvement in decision-making and self-care activities within their chronic illness plans of care?* An ethnographic pilot study first addressed questions (3a) and (3b). This third project was conducted to test the feasibility of methods. Type 2 diabetes was again chosen as an exemplar chronic illness and 3 nursing home residents were purposively recruited to participate based on their ability to communicate clearly and provide independent informed consent. Domain analysis, explanatory modeling, and descriptive statistics were used to analyze the data. Four themes emerged: *Too many shots, No choice, Fewer Sticks,* and *More knowledge through communication*. Residents described having diabetes as meaning they received too many needle sticks including finger sticks for glucose monitoring and insulin injections; and they perceived they had no choice in the matter whatsoever. They expressed that if they had a choice they would decrease and change the timing of sticks, and learn more about their choices. This small study suggested that some nursing home residents had definite preferences in their chronic illness regimens but were not being provided with opportunities to express them and did not understand they could express them in a way that would have any impact. These findings led to the overall research questions of the final study which encompassed

defining the opportunities available in the nursing home for residents to participate in health care and how those opportunities could be enhanced.

Although the methods of the ethnographic pilot study proved feasible, this researcher was privileged to be provided access to qualitative data previously collected for a similar qualitative study of nursing home resident chronic illness management choices, and opted to analyze this existing rich data and conduct the ethnography in her future work. The secondary analysis study was the fourth and final project and addressed research question 3 using a qualitative descriptive design and qualitative content analysis. The parent study sampled 31 nursing home stakeholders including 5 residents, 7 family members of residents, 8 advanced practice registered nurses, 5 physicians, and 6 administrators.

In response to research questions (3a) and (3b), stakeholders, as a whole, voiced many opportunities for residents to participate in chronic illness care decision-making and self-care activities, however, they noted several limitations. For example, a resident and family had choices as to which medication to take or when to take it, but the choices were limited by the medications on the nursing home pharmacy formulary and the insurance formulary, as well as the number of available staff to accommodate the resident's preferences on timing of medication administration. Opportunities to provide choices were also plentiful including care plan meetings, admission meetings, and provider visits; however, the formats of these meetings were inconsistent and often did not include the resident or health care provider, which diminished the chances of productive resident-provider interactions to promote self-management.

In response to research question (3c), stakeholders described many qualities APRNs currently possessed that enhanced resident involvement including: being available to residents and staff; spending time listening and speaking with residents,

communicating to residents that they were valued participants in care; and collaborating with physicians and staff to provide continuous, quality care. Stakeholders also described additional expected qualities in a nursing home APRN, such as seeing as many patients as possible in a given period of time, which, although necessary for financial and regulatory purposes, seemed to conflict with the previously described goal of spending more time with each resident.

An overall perception of disinterest by residents, family and health care providers was communicated by this group of stakeholders. As a whole, they perceived that most nursing home residents were not interested in being involved in chronic illness care decisions or activities; they felt that although most families were involved, there was a trend toward less involvement and dysfunctional over-involvement of families; and that health care providers, primarily physicians, were seen as unavailable or too busy to spend adequate time with the resident, family, and facility staff.

The findings of the study also illuminated conflicting and unattainable goals expressed by stakeholders and interpreted by this study as barriers to the provision of resident-directed care. The data revealed that although all residents sampled were very interested in participating in health-related decisions and activities, an overall goal expressed by several residents and recognized by other participants as well, was to get well enough to return home, which generally did not happen with long-term residents (all residents in the sample and referred to in the study were long-term residents). The goals of involved or over-involved family members were described as sometimes being unrealistic, i.e., wanting the resident's condition to improve greatly or not to decline in any way – again, improbable goals. Finally, the goals of health care providers and administrators were perceived as wanting to provide high quality health care with high quality outcomes, while keeping hospitalization rates down and overall costs low. These

are admirable but difficult goals to meet with an underlying shortage of funds and available qualified professionals and if "high quality outcomes" are not well-defined, understood, or agreed upon by all involved.

Thus, the data showed there was little consensus on the overall purpose and goals of the nursing home admission among stakeholders. This was interpreted as the problem or the enigma of nursing homes contributing to the lack of involvement of residents in their care, despite the efforts of stakeholders to be involved or to promote involvement. Wagner's Chronic Care Model stresses basic elements of chronic illness self-management that were not present in this data, possibly because overall, residents were not expected to self-manage. The findings supported the Chronic Care Model philosophy that there must be consensus by all parties on the problem or purpose of care and there must be attainable goals, continuous support to meet goals, and sustained follow-up to re-evaluate and adjust goals as needed for resident self-management to be realized. A modified Chronic Care Model for the Nursing Home was proposed emphasizing the use of community and facility support groups (and effective care plan meetings) for residents, families, and health care providers to discuss and agree upon the purpose of the nursing home admission, attainable goals, and chronic illness management principles focused on resident preferences for treatment and quality of life.

IMPLICATIONS

The implications of the four research projects undertaken in this dissertation are presented in Table 10.

Clinical implications

The quantitative review of the literature found diabetes management practice in nursing homes as inconsistent with current clinical practice guidelines and suggested a

need for better use of evidence-based practice and resident decisional and self-management support. Additional provider education regarding current clinical practice guidelines, discussion of the guidelines and care options with interested residents, and better documentation of deviations from guidelines when individualizing care was suggested. The qualitative meta-synthesis stressed the need to strengthen the productive interactions between residents and health care providers. Suggestions were made to question residents regarding their preferences for involvement and to determine what they perceived as the purpose of being involved. The results of the synthesis called for more time to be spent with residents to evaluate their needs and preferences, encourage them to participate if they so desired, and to cultivate a trusting relationship. The results of the ethnographic pilot study suggested a need to inform interested residents of opportunities for involvement in their chronic illness plans of care. The findings from the secondary analysis proposed several additions to the Chronic Care Model and suggested the following clinical actions:

1. The initiation of support groups within the nursing home and in the community to assist residents and family members to prepare and cope with the stressors and changes that occur with nursing home admission, financially, socially, emotionally, and physically;
2. The use of chronic illness support groups within the facility to encourage residents and families to learn more about their illnesses, treatment options, and expected outcomes and to assist with realistic goal-setting and attainment;
3. A large scale media push to educate the general public on the purpose, benefits, and goals of nursing homes to reduce the guilt, fear, and dread often associated with nursing home admission as well as the negative professional

stigma which likely plays a role in low numbers of health care providers and decreasing federal and state funding;

4. Education and support for health care staff and medical care providers on communication techniques to ensure a consensus of all team members (including the resident and family) on purpose, goals, and evidence-based practices; and
5. Improvement of care plan meeting effectiveness by ensuring that all residents and families are informed of the purpose of the meeting, the meeting is set at a time convenient to resident and family, they are reminded and encouraged to participate, and that health care providers, trusted and familiar to the resident and family are also present. The care plan meeting should focus on discussion of the purpose of the admission for the particular resident, the setting of resident-directed attainable goals, and follow-up of those goals.

Research implications

This work identified several areas where additional research would be useful. Authors of the studies included in the systematic review of nursing home diabetes management literature agreed that further study was necessary into the association between certain management practices such as levels of glucose monitoring and maintenance of certain glucose levels and specific resident outcomes, including health outcomes and quality of life outcomes. The qualitative meta-synthesis suggested a need for research focused on what older-adults perceive as the purpose of involvement. Are they interested in actually making health care decisions or is it more the recognition of personhood and the dignity of inclusion they seek? This study also stressed the value of the advanced practice nurse as a major contributor to patient-directed chronic illness care

and noted the need to measure provider time spent with patients and the quality of communications with the associated patient health, quality and economic outcomes. The final study paved the way for developing an intervention study to investigate the effects of additional resident/family/provider support groups and education on resident and family quality of life outcomes and the alignment of outcomes with resident preferences. It also encouraged further work investigating ideal future medical management models of care, testing different roles played by advanced practice registered nurses, physicians, and physician assistants and their effects on resident-directed outcomes.

Health policy implications

The nursing home system has been undergoing changes over the last 25 years to improve quality of care, mostly brought about by legislation aimed at safeguarding the health and well-being of this vulnerable population. The entrance of the Baby-boom population into this system should prompt legislators to pause and review some of these regulations and allocations of funds to ensure they do not impede the ability of the system to provide the choices, the professional care, and the financial resources necessary to support the dignity and autonomy of nursing home residents. Additionally, there is a need for lawmakers to recognize the importance of innovative research to empirically determine the health, quality of life, and financial outcomes of the provision of resident-centered care. Finally, health care provider goals of providing high quality, person-centered medical care with a dwindling workforce, should be supported by legislation to allow qualified APRNs to provide care for these residents to the full extent allowed by their education and expertise.

CONCLUSIONS

This dissertation work found that resident-directed care was not common in the facilities sampled. Nursing home stakeholders as a whole perceived that very few residents were interested in participating in their health care regimens and decisions. Thus, it was concluded that self-management in nursing homes was not expected and as a result was not sufficiently supported and encouraged. Results, however, also suggested that some current nursing home residents were interested and motivated to self-manage and that self-management improved self-esteem and had the potential to improve quality of life outcomes. Research in other chronically ill populations has shown that involvement in self-management improves health and quality of life outcomes and that more and more chronically ill older-aged adults may be demanding the right to self-manage. This research has suggested modifications to the Chronic Care Model for use in nursing homes. It has opened the door for intervention studies to test the modified model, adding more support groups for stakeholders, encouraging the principles of self-management, and measuring resident outcomes and their congruence with resident preferences. It is hoped that this modified model will assist in guiding further research informing the systematic implementation of person-centered chronic illness care in the nursing home resulting in quality of life outcomes as closely aligned with resident preferences as possible.

Table 1: Elements of person-centered care

Element	Source	Nursing Home Operational Definitions	Source
Person-centered care Services that cultivate relationships, honor right to privacy, respect, self-determination, and individuality.	Love & Kelly, 2011	Resident-centered, Resident-directed, culture change Knowing each adult as a person; Putting the individual before the task Providing avenues for decision-making	Robinson & Rosher, 2006 Bowers et al., 2009
Holism Consider the whole person (physical, mental, emotional, intellectual, spiritual)	Morgan & Yoder, 2012	Meaningful activities that promote a sense of belonging, purpose, trust Views the patient in the context of relationships with family and community	Love & Kelly, 2011 Feinberg, 2012
Personhood Uniqueness Value	Crandall et al., 2007 Kitwood, 1997 Sloane et al., 2004	Considering the person, not the disease; Respect of space, time, and person; Dignity; Recognition by life history narratives, photos	Morgan & Yoder, 2012; McCormack, 2003
Knowing the Person Meaning they ascribe to illness	Crandall, et al., 2007 Morton, 2000 Talerico et al., 2003	Knowledge of culture, beliefs, traditions, habits, & preferences; Consistent staff assignments; Teams of staff for small groups of residents	Morgan & Yoder, 2012 Love, 2010
Choice & Autonomy Empowerment Sharing of power and responsibility	Crandall et al., 2007 Mead & Bower, 2000	Resident direction; Collaborative decision-making; Incorporating residents into care-planning; Identifying meaningful choices; Respecting preferences	White, et al., 2012 Feinberg, 2012 McCormack, 2003 Hickman, 2004

Table 1: Elements of person-centered care

Element	Source	Nursing Home Operational Definitions	Source
Service (Medical/Nursing) Accessibility Flexibility Collaboration	Talerico, et al., 2003 Love, 2010	Education for residents/families; Culture recognition; Resource availability; Interdisciplinary collaboration	Love, 2010 Feinberg, 2012
Therapeutic/caring relationships	Crandall, et al, 2007 Brooker, 2004	Close relationships with staff; Constant socialization opportunities; Listening	White-Chu et al., 2009 Love & Kelly, 2011
Supportive physical environment	Crandall, et al., 2007 Osborn, 2001	Home-like atmosphere; Restaurant style dining; Privacy	White-Chu et al., 2009
Supportive organizational environment	Crandall, et al., 2007 Love, 2010	Decentralized decision-making Staff empowerment; Staff career advancement; Staff training/educational opportunities	Love, 2010 Love & Kelly, 2011 Bowers et al., 2009
Accountability/Evaluation/Quality	Love, 2010 Love & Kelly, 2011	Satisfaction surveys Staff turnover report State surveyor reports; Quality Improvement reports	Love & Kelly, 2011 Bowers et al., 2009

Table 2: Managed care guidelines for the elderly

Guideline	AMDA (2008) For LTC Setting	AGS (2003) For Older Persons	ADA (2010) For Older Adults
Relaxed DM Management Indicated	Life expectancy < 5 yrs Hypoglycemia unawareness or recurrent episodes Anorexia, gangrene, malignancy, severe dementia or dependent feeding	Frail with high burden of: Comorbidities < 5 yr life expectancy Difficulty adhering to treatment	Limited life expectancy History severe hypoglycemia Advanced complications Many comorbidities
Blood glucose monitoring	No medications or oral agents only: twice daily, 2-3days/wk 1-2 insulin injections/day: twice daily, 3-4 days/wk 3 insulin injections/day: four times daily	Individualized	Capillary blood glucose may be a useful tool for those w/ frequent hypoglycemic episodes
A1C	<u>Minimally impaired/ life expectancy > 5yrs:</u> Target: 7% or lower Every 6 mo if well controlled Every 3 mo if poor control	<u>Healthy:</u> Target: 7% or lower Every 12 mo if stable & meeting target Every 6 mo if target not met	<u>Healthy:</u> Target < 7% Every 6 mo
	<u>Life expectancy < 5 yrs & risks outweigh benefits:</u> Target: 8%	<u>Frail:</u> Life expectancy < 5 yrs: Target: 8%	<u>Limited life expectancy:</u> Less stringent
Diet	Regular diet; consistent timing	Not specified	Not specified
Eye Exams	Initially & 1-2 x/year	Initially & 1-2 x/year	Not specified
Foot Exams	Yearly or more often if PVD or PND	Yearly	Not specified
Hypertension	Target: 130/80 ACE inhibitors Monitor serum creatinine, potassium and GFR Check BP monthly	Target: 130/80 (if tolerated) If on ACE inhibitors: monitor creatinine, potassium	Target: < 130/80 ACE inhibitors or ARB Monitor renal function
Peripheral Neuropathy	Urine microalbumin/creatinine: Annually if < 30µg/mg Every 6 mo if > 300µg/mg	Microalbumin initially and yearly	Individualized
Cardiovascular Disease	Aspirin, Plavix or Aggrenox daily (unless contraindicated)	Aspirin daily (unless contraindicated)	Treat with aspirin if life expectancy > 5 years
Dyslipidemia	Target: LDL-C< 100, HDL-C > 40; Trig < 150 Treat with statin only after glucose control measures implemented	Target: LDL-C< 100, HDL-C > 40; Trig < 150 Treat with statin (if not contraindicated)	Target: LDL-C < 100 Treat with statin if life expectancy > 5 yrs

ADA (American Diabetes Association); AGS (American Geriatrics Society); AMDA (American Medical Directors Association); BMI (Basal metabolic (Body mass index); DM (Diabetes mellitus); LTC (Long term care); PND (Peripheral neuropathy disease); PVD (peripheral vascular disease)

Table 3: Characteristics of diabetes management studies

Author/ Country	Purpose/ Guidelines Used	Setting & Sample	Design/Tools	Major Findings	Conclusions
Feldman et al., (2009) U.S.	Examine current state of DM management in NHs AMDA 2008 ADA 2003 AHA	372 residents with DM in 13 NHs, 6 states (CA, CT, FL, IL, IN, MA, TX) 61.37% female 24 DONs & MDs	Interview, survey created by authors Chart review; form created by authors	7.1% (NHs) had A1C policy 15% had algorithms policy 1 (NH) with QI tool for DM policy 30.8% (NHs) with BGM policy 87.63% incidence delusions vs. 3.7% (national average) 10.76% with skin ulcers 3% with infected wounds 1% hospitalization due to hypoglycemia 6% w/ hypoglycemia symptoms	DM care did not meet ADA standards (adults) A1C goals met but not FBS goals → dangerous varying BG Specific NH guidelines for care of DM needed Too many different approaches – need standardized tools that adhere to CPGs
Quinn et al., (2009) U.S.	Explore role of admission dementia status on 5 DM related procedures (A1C, FBG, ophthalmic exam, lipids & creat) Saliba, D., et al., 2005	399 newly admitted res with DM in 59 Maryland NHs 70.9% female	Chart review, Medicare admin claims records Tools not described	Pts without dementia received more procedures than those with dementia Pts without dementia have > increase in procedure rates post admission than those with dementia DM prevalence: 17.7% (~404/2285, parent study)	NH structured environment may ↑ DM monitoring, especially for pts. without dementia NH admit better for pts. without dementia Research on specific treatments needed to ↑ benefit while ↓ risk & cost
Pandya et al., (2008) U.S.	Determine SSI use in NH pts. AMDA 2008 ADA 2008 AACE 2004	9,804 pts. with DM, aged 65 yrs or > 63.1% female	Chart review Database, MDS data Tools not specified	56% on insulin 54% on insulin, initially on SSI 59% starting insulin after admission on SSI 83% continued on SSI	SSI use highly prevalent & persists once initiated Frequent use of SSI inconsistent with all GLs Outcome studies needed

Table 3: Characteristics of diabetes management studies

Author/ Country	Purpose/ Guidelines Used	Setting & Sample	Design/Tools	Major Findings	Conclusions
Sjoblom et al., (2008) Sweden	Investigate feasibility of withdrawing DM meds in elderly NH pts w/A1C </= 6.0% Not reported	658 res in 17 NHs 32 T2DM (intervention) 66 T1DM (control) 63.1% female	Quasi-experimental (pre-test/post-test, non-equiv groups) Chart review Hemoccue® for A1C	Hi freq hypoglycemia in T2 DM pts baseline 24/32 (75%) with successful withdrawal of DM meds 2 died (cause not specified) 4 withdrew due to hyperglycemia 2 withdrew due to family concerns DM prevalence: 15% (98/658)	Withdrawal of DM oral meds & withdrawal or ↓ insulin safe in elderly NH pts with tight BG control Need systematic drug reviews
Holt et al., (2007) U.S.	Explore physician management of pts with T1DM or T2DM in NHs & compare to ADA standards for outpatient adults ADA 2006 AGS 2003	108 residents with T1 or T2DM in 11 NHs in midwestern US 79% female	Chart review	98% monitored BG; 38% met goals 67% achieved A1C goal 94% monitored BP with 55% meeting goal 31% had yearly lipids 7% had microalbuminuria testing 42% received ophthalmic exams 87% had foot exams	Care of elderly with DM in NHs does not meet ADA standards of care for outpatient adults Specific guidelines needed for NH pts with DM
Horning et al., (2007) U.S.	Determine CPG adherence in NH pts receiving DSM (disease state management) vs. traditional DRR (drug regimen review) ADA 2005	107 DSM pts in 2 NHs 304 DRR pts in 4 NHs 129 pts had DM 75% female	Chart review, researcher created data collection form Database review, MDS	For DM diagnosis: DSM pts had better adherence to CPG's than DRR pts (A1C of </= 7% (86.2% vs. 62%) (p<.05) DM Prevalence: 31.4% (129/411)	No financial incentives or federal guidelines to promote adherence to CPGs in NHs Higher rate of adherence to CPGs with DSM vs DRR

Table 3: Characteristics of diabetes management studies

Author/ Country	Purpose/ Guidelines Used	Setting & Sample	Design/Tools	Major Findings	Conclusions
Meyers et al., (2007) U.S.	Assess prevalence of DM & mean A1C of pts in NHs & describe self-reported DM management goals of providers AMDA 2005 EDWP 2004 AGS 2003	10 MDs, 8 NPs from 1 practice including 20 NHs (778 pts) 168 DM pt charts reviewed	Interviews Survey Chart review	Mean A1C = 7.1% +/- 1.2 overall 20% with no A1C done in 12 months ↑ A1C assoc with ↓ age, ↓ insulin use, ↑ glucose monitoring & ↑ attending DM clinic 72% providers reported less aggressive DM management in NH pts than community dwelling pts 44% reported A1C goal between 8-9% Provider perception of life exp & health status did not significantly affect A1C DM Prevalence: 21.6% (168/778)	Possible concerning subclinical hypoglycemia indicated due to (A1C=6.7%) in older pts Further research needed for older vs younger pts Further research needed into decision-making process in individualizing care
Aspray et al., (2006) U.K.	Perform a health-equity audit of DM management in elderly NH pts BDA 1999	1604 residents of all NHs in Newcastle upon Tyne, UK 185 with DM	Interviews Surveys Chart reviews Data collection forms & questionnaire created by researchers	75% using CBG monitoring Unnecessary high rate CBG in res w/diet control or oral meds only BP recorded – 44-69% yearly Weights recorded in 95% No recommended standards in place Staff knowledge of DM management very low – especially among non-licensed staff DM Prevalence: 11.5% (185/1604)	UK Diabetes Register underestimates number of DM cases (3.5 vs. 11.5%) Inappropriate high rates of glucose monitoring & low eye screening Staff lacked DM training/education

Table 3: Characteristics of diabetes management studies

Author/ Country	Purpose/ Guidelines Used	Setting & Sample	Design/Tools	Major Findings	Conclusions
Gill et al., (2006) New Zealand	Explore prevalence & describe management of DM in NHs in New Zealand Not reported	168 residents w/DM from 54 NHs, randomly selected 65% female	Structured interviews developed by researchers Chart review	Other comorbidities: 5 (mean) 7.5 (mean) meds prescribed 45% taking oral glucose meds 28% on diet alone 27% on insulin Mean A1C = 7.3% Blood glucose levels often not checked in possible hypoglycemic episodes DM Prevalence: 11.7% (183/1567)	Prevalence of DM less than in US Quality of care indicators in DM pts satisfactory Staff had poor recognition of need to increase frequency of BG on sick days
Mader et al., (2006) U.S.	Create an algorithm for CBG testing in NHs AGS 2003 ADA 2002 AMDA 2002	101 DM pts of VA NH & VA rehab unit 2% female	Chart review CBG testing protocol developed through review of literature, GLs & pilot-testing	69% pts received orders to use CBG protocol 19% pts had orders for SSI 78% pts using protocol were eligible for advancement to less frequent monitoring No significant change was found in CBG testing rates before, during or 12 months after study DM Prevalence: 53% (101/191)	CBG protocol likely successful if adequate clinical support Future research should include effect on testing frequency & outcomes No data exists regarding whether intensive DM management improves outcomes
Allsworth et al., (2005) U.S.	Assess prevalence of racial & ethnic disparities with regard to DM treatment of pts in NHs ADA 2003	50,427 NH residents with DM in NY, SD, KS, MS & OH (1993-1997)	Database review; MDS, SAGE Chart review	Blacks & Hispanics were younger, had ↑ rates of blindness, amputation & cognitive/physical impairment than Whites Blacks & Hispanics had ↓ total meds & DM meds than Whites Blacks & Hispanics had ↑ rates of insulin use & ↓ rates of sulfonylurea use than Whites DM Prevalence: 20.1% (66,093/~328,820)	More research needed to determine why some NH pts are less likely to receive DM meds

Table 3: Characteristics of diabetes management studies

Author/ Country	Purpose/ Guidelines Used	Setting & Sample	Design/Tools	Major Findings	Conclusions
McNabney et al., (2005) U.S.	Determine self-reported DM management patterns among NH physicians AGS 2003 AMDA 2002	255 AMDA member physicians (37% response rate)	Survey presenting 3 pt profiles (functionally impaired; cognitively impaired; both functionally & cognitively impaired)	Special diet, lipid panels, routine ophthalmology less likely for pts with both functional and cognitive impairments ($p<.01$) In all pts, regardless of level of impairment: Accepted A1C < 9% in 9-37% Special diet "Always ordered": 7-46% SSI "Always ordered": 4-13% FS "Never /Rarely checked": 2.5-47% Lipids "Never/Rarely checked": 2-41% Eye exams "Never/Rarely": 2-43% Foot exams "Never/Rarely": 1-23%	Less aggressive DM management in both functionally & cognitively impaired pts Research needed into actual practice patterns based on chart review Research needed into impact of practice patterns on outcomes
Berry et al., (2004) U.S.	Assess foot care provided to residents with DM in a long-term care facility ADA 2000	17 residents (15 T2DM, 2 T1DM), 179-bed LTC facility, Midwest	Database review Chart review MDS Diabetic Foot Care (Rantz & Popejoy, 1998); Foot care history instrument created by researcher	59% with foot problems on admission 100% foot exams done on admit, 1 pt assessed weekly, 0% assessed daily 9/10 of above developed skin breakdown None had 3 month follow up podiatry visits 1 with podiatrist exam in chart 6 referred to podiatrist DM Prevalence: 16.2% (29/179)	Gap between established standard (ADA) and actual care Recommend education of staff re standards and footcare CQI to improve care plans and interventions

Table 3: Characteristics of diabetes management studies

Author/ Country	Purpose/ Guidelines Used	Setting & Sample	Design/Tools	Major Findings	Conclusions
Goldberg (2003) U.S.	Compare effects of regular diet (per 2002 ADA standards) & NCS diet in T2DM pts in NHs ADA 2002	34 residents, 4 NHs, western NY Older than 65 T2DM NCS diet orders A1C </= 8% 76% female	Quasi-experimental, multiple group, time-series, A1C & Albumin Dietary intake tool developed by researchers	No significant differences in A1C, serum albumin, % IBW (or other nutritional measures) between control and experimental groups	Nutritional status was maintained when diet was changed from NCS to regular over 3 month period Nutritional status did not improve in either group
Pham et al., (2003) France	Assess prevalence of DM, patterns of care & outcomes in NHs; Compare a non-DM & DM group of residents on ADL function & mortality over time ANAES 1999	494 res, 73 with DM, in 2 (120-bed) NHs and 2 (40-bed) residential homes in Bordeaux, France	Chart review Katz ADL scale; A.G.G.I.R. composite scale for cognitive & ADL tasks; A1C assay using HPLC method	Residents with diabetes: A1C within guidelines for 23.3% A1C never performed in 26% A1C > 8% in 20.5% 32.9% received eye exams 75% on a prescribed diet BP measured 3-4x/yr in only 53.4% Change in ADL dependency between DM group & control not different Mortality rate higher in control vs. DM group DM Prevalence: 14.8% (73/494)	DM management needs to be improved Mortality rate & functional dependency not influenced by quality of DM control

Table 3: Characteristics of diabetes management studies

Author/ Country	Purpose/ Guidelines Used	Setting & Sample	Design/Tools	Major Findings	Conclusions
Douek et al., (2001) U.K.	Investigate DM management of NH residents to determine if policies & procedures tailored to NH residents are present BDA 1999	Nurse managers from 40 NHs in Weston General Hospital catchment 1008 residents (85 with DM)	Structured interviews Tool developed by researchers	7/40 NHs (17.5%) had written DM management protocol 16 NHs (40%) had clear hypoglycemia event protocol CBG measured using visual test strips (45%); electronic meters (55%) Meters shared between residents; no meter calibration policies DM Prevalence: 8.4% (85/1008)	Inconsistent DM care Poor knowledge of treatment for hypoglycemia & sick days Infection risk high due to sharing of glucometers Providing care guidelines & education should improve DM care
Hauner et al., 2001 Germany	Use A1C to estimate % of NH residents with undiagnosed DM & assess quality of metabolic control in those with known DM EDPG 1999	39 NH DONs 1936 residents in rural county of Heinsberg, Germany; 507 w/DM; 20/39 NHs had A1C measured	Survey Interviews Questionnaire completed by DONs A1C, using Tina-quant®	37% of known DM res on insulin Mean A1C in known DM, >/= 60 yrs: 7.3 +/- 1.5% Mean A1C in unknown DM: 6.1+/- 0.9% 16.7% known DM: A1C > 8.5% 47.2% unknown DM: A1C > 6.1% 8.5% unknown DM: A1C > 7.0% DM Prevalence: 26.2% (507/1936)	Prevalence of possibly undiagnosed DM in elderly NH residents is high (39%) 8.5% may require treatment Quality of metabolic control better than expected

Table 3: Characteristics of diabetes management studies

Author/ Country	Purpose/ Guidelines Used	Setting & Sample	Design/Tools	Major Findings	Conclusions
Spooner et al., (2001) U.S.	Evaluate prevalence of DM & correlating factors of DM management ADA 1999	75,829 residents with DM MDS data from 1992-1996	Database review, SAGE RAI & MDS assessment instruments	DM prevalence = ~17.3% (Hispanics: 28%; Blacks: 26%) 47% received no anti-DM meds Age inversely related to receipt of anti-DM meds Blacks 13% less likely to receive DM meds than Whites Low BMI inversely related to receipt of DM meds DM Prevalence: ~17.3% (75,829/ 437,128)	Nearly half residents with DM in LTC receive no meds
Tariq et al., (2001) U.S.	Compare glycemic response of T2DM NH residents on a regular diet vs. NCS diet ADA 1999	28 residents w/ T2DM, 200-bed SNF in St. Louis, MO Regular diet – intervention NCS diet – control 68% female	Quasi-experimental, non-random, time-series Albumin – dye binding; FBG – glucose dehydrator; A1C – liquid chromatography	3 mos after diet change, no difference in BMI, FBG, BF, Alb & Hgb between 2 groups A1C not different in changes at baseline, 3 mos or 6 mos between 2 groups Increased meds required by both groups Insulin increased in 5 residents (mean = 5 u)	T2DM residents in LTCs can be managed on a regular diet with no significant differences in blood glucose or A1C Glucose levels & meds can be adjusted to allow a regular, non-restricted diet

Table 3: Characteristics of diabetes management studies

Author/ Country	Purpose/ Guidelines Used	Setting & Sample	Design/Tools	Major Findings	Conclusions
Taylor et al., (2000) U.K.	Examine prevalence of known DM & patterns of DM care in NHs BDA 1999	98 DONs, Sheffield, UK 70 returned surveys 233 residents with DM	Surveys Interviews Researcher created questionnaire	Response rate: 71% DM prevalence: 8.8% Only 1.7%) RNs DM certified 50% NHs had no opportunity to self-manage Only 14% NHs had BG meters DM assessment tool used by 24% Only 67% reported regular visits by MD for DM management review 14 reported no DM management review by MDs DM Prevalence: 8.8% (233/2648)	True or total prevalence may be much higher DM management poorly structured Educational needs of staff not met British Diabetic Association guidelines may greatly improve quality of care

A1C (Glycosylated hemoglobin levels); AACE (American Association of Clinical Endocrinology); ACE (American College of Endocrinology); ADA (American Diabetes Association); AHA (American Hospital Association); AMDA (American Medical Directors Association); ANAES (*Agence Nationale d'Accréditation et d'Evaluation en Santé* – French Diabetes Agency); ASA (Aspirin); BDA (British Diabetic Association); BG (Blood glucose); BGM (Blood glucose monitoring); CBG (Capillary blood glucose); CMD (Certified Medical Director); CPGs (Clinical practice guidelines); DM (Diabetes mellitus); DONs (Directors of nursing); EDPG (European Diabetes Policy Group); EDWP (European Diabetes Working Party); FBG (Fasting blood glucose); FS (Fingerstick); MDs (Medical doctors); MDS (Minimum Data Set); NHs (Nursing homes); NPs (Nurse practitioners); Pts (Patients); QI (Quality improvement); RCT (Randomized controlled trial); SSI (Sliding scale insulin); T1DM (Type 1 Diabetes mellitus); T2DM (Type 2 Diabetes mellitus); VA (Veteran's Administration)

Table 4: Summary of management practices across studies

Management Practice	Weighted Mean	# Studies Reporting	# Residents Overall	Studies	
Receiving no medications	44.6%	10	130,659	Feldman et al. Sjoblom et al. Aspray et al. Gill et al. Mader et al.	Allsworth et al. Pham et al. Hauner et al. Spooner et al. Taylor et al.
Receiving oral anti-diabetes agents only	36.5%	4	552	Sjoblom et al. Aspray et al.	Gill et al. Mader et al.
Receiving oral anti-diabetes agents	28.3%	6	54,099	Holt et al. Allsworth et al. Pham et al.	Douek et al. Hauner et al. Taylor et al.
Receiving insulin	39.0%	14	65,029	Feldman et al. Pandya et al. Sjoblom et al. Holt et al. Meyers et al. Aspray et al. Gill et al.	Mader et al. Allsworth et al. Goldberg Pham et al. Douek et al. Hauner et al. Taylor et al.
Receiving oral anti-diabetes agents & insulin	14.9%	3	10,003	Pandya et al. Sjoblom et al.	Mader et al.
Restricted diet	72.4%	5	740	Feldman et al. Goldberg Pham et al.	Tariq et al. Taylor et al.
Sliding scale insulin used	54.2%	4	10,385	Feldman et al. Pandya et al.	Holt et al. Mader et al.
Blood glucose monitored per Guidelines	73.4%	6	803	Holt et al. Meyers et al. Aspray et al.	Gill et al. Mader et al. Pham et al.
A1C monitored per Guidelines	79.7%	4	517	Holt, et al., Meyers, et al.	Gill, et al. Pham, et al.
BP monitored per Guidelines	73.0%	4	534	Holt, et al. Aspray, et al.	Gill, et al. Pham, et al.
Eye exams per Guidelines	34.6%	4	534	Holt et al. Aspray et al.	Gill et al. Pham et al.
Podiatry exams per Guidelines	68.9%	5	551	Holt et al. Aspray et al. Gill et al.	Berry et al. Pham et al.

Table 5: Typology of qualitative findings (as described by Sandelowski & Barroso, 2007, Ch. 5)

Type of Finding	Description	Rating Assigned
No Finding*	Presentation of un-interpreted data (quotations, stories, incidents, etc.)	1
Topical survey*	Staying close to the surface of the data; presentation in the form of lists or categories with quotations to support the categorization	2
Thematic Survey	More in depth description of categories and themes, where themes are used to organize the data, including some interpretation by the researchers	3
Conceptual thematic description	Themes and concepts, often from theoretical frameworks, are used to explain data rather than only to organize data; interpretation casts new light on existing data	4
Interpretive explanation	The most integrated of findings, presents a detailed description of a model or argument that explains causation or origination of events or experiences	5

*Studies appraised in these categories were not included in the metasynthesis.

Table 6: Characteristics and contributions of decision-making studies

Author/ Year/ Country	Purpose	Setting/ Sample	Theory/ Type Findings/ Appraisal Value	Design/Methods	Findings/Themes
Bastiaens et al., 2007 11 European countries	Explore views of older adults on involvement in primary care	Primary care clinics; 406 primary care pts.; Aged 70-96 yrs.	Not stated/ Thematic survey/ 3	Qualitative descriptive; Semi-structured Interviews; content analysis	Provider factors: show interest, give clear information, be trustworthy & supportive; offer enough time Pt. factors: differ in information needs, interest in health, ability to deal with medical care, understanding of information, readiness to participate in decisions
Belcher et al., 2006 USA	Describe views of older adults on participation in medication decision-making	Senior centers, physician offices 51 chronically ill pts. Aged 65-89 yrs.	Decision-making framework/ Thematic survey/ 3	Qualitative, narrative interviews, constant comparative analysis	High variability in perceptions of ability to play a role in medication decisions Physician attitudes and trustworthiness can both encourage & impede involvement Health care system problems: lack of time, insurance, multiple providers, too much new medication information
Hughes & Goldie, 2009 Northern Ireland	Explore resident medication adherence & involvement in medication decisions	NH 17 residents Mean age 80.5 yrs. 8 GPs 9 Nurses	Not stated/ Thematic survey/ 3	Qualitative descriptive; Semi-structured interviews, focus groups; constant comparison	Main theme: control Residents accepted complete control of medications by providers without question; Residents' minimal involvement in medication decisions influenced by provider desire to control routine and organization of system for resident safety

Table 6: Characteristics and contributions of decision-making studies

Author/ Year/ Country	Purpose	Setting/ Sample	Theory/ Type Findings/ Appraisal Value	Design/Methods	Findings/Themes
Loffler et al., 2012 Germany	Examine how older-aged adults cope with multiple chronic diseases	Community dwelling 19 multi-morbidity pts. Aged 65-85 yrs.	Coping framework/ Interpretive explanation/ 4	Grounded theory; narrative interviews	Coping at social level: effort toward continuing a meaningful life, maintaining autonomy; some unable to do this, felt alone, abandoned Coping at emotional level: anxiety & desperation vs. strength & euphoria Coping at practical level: keeping disease controlled through self-education; wary of drug adverse effects; less adherent to recommendations
Schoot et al., 2005 The Netherlands	Describe demand-oriented care as seen by older-aged patients & family	Community dwelling; 5 older-aged chronically ill persons Aged 50-60 yrs. 2 family caregivers	Grounded theory/ Interpretive explanation/ 5	Grounded theory; focus groups; comparative analysis	Overarching theme: Recognition Recognition by provider of pt. values regarding personhood (uniqueness, comprehensiveness, continuity of life, fairness, & autonomy) & health care partnership needs (equality, partnership, interdependence). Feeling recognized reinforces autonomy, self-esteem, & participation; non-recognition leads to frustration, anger, feeling inferior
Schulman-Green et al., 2005 USA	Explore how older adults discuss & plan life & health goals during clinical encounter	Community dwelling; 42 chronically ill pts. Mean age: 81 yrs. 11 clinicians	Not stated/ Conceptual thematic description/ 4	Qualitative descriptive; Focus groups; interview guides; content analysis	Goal setting not a priority due to limited time Visits focused on symptoms Both groups presumed the other not interested in discussing goals Pts. & providers assumed all patient goals were the same Pts. believe discussion of goals too intimate to discuss with unfamiliar clinicians

Table 6: Characteristics and contributions of decision-making studies

Author/ Year/ Country	Purpose	Setting/ Sample	Theory/ Type Findings/ Appraisal Value	Design/Methods	Findings/Themes
Shawler C., et al. 2001 USA	Examine change in resident's decision-making autonomy over time	NH 1 female resident Age: 88 yrs. 1 family member 3 staff members	Decision-making framework/ Interpretive explanation/ 5	Ethnography; case analysis participant observation, event analysis, repeated interviews	Resident wanted preferences honored Felt involvement in decision-making dwindling as time passed Preferred to be made aware of decisions that were being made Establish supportive interdependence environment as opposed to paternalistic dependency

Patient=Pt.; Years: yrs.; Nursing home: NH; GP: general practitioner

Table 7: Concepts of the Chronic Care Model adapted for nursing homes

CCM Concept	Concept Description Adapted for NHs
Health Systems	Administrator philosophy, facility culture, and facility regulatory environment determine the degree of priority placed on and the quality of *productive interactions* between the *practice team* (physicians/APRNs) and the *patient* (resident/family)
Decision Support	Sharing of expert information, including evidence-based guidelines and exceptions to those guidelines, providing a venue for *productive interactions*, improving the residents' comfort level and willingness to participate in self-management
Self-management Support	Acceptance of the resident as director of his/her own health care management; provision of ongoing education, support, and encouragement to participate
Patient	Nursing home resident/family member informed of illness treatment options and "activated" or aware of the importance of their role in chronic illness care
Practice Team	Physicians and APRNs focused on placing the resident at the center of chronic illness care and providing proactive rather than problem-oriented care
Productive Interactions	Quality, frequency, and mode of communication and resulting understanding and motivation between providers and resident/family

Table 8: Nursing home stakeholder demographics

	Residents (N=5)		Family (N=7)		Physicians (N=5)		APRNs (N=8)		ADMINs (N=6)	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)
Age (yrs)										
Mean (SD)	87.4	(7.2)	66.3	(13.7)	50.5	(15.2)	49.4	(13.7)	44.5	(9.4)
Range	80-97		47-83		35-65		31-64		30-59	
Gender										
Male	1	(20)	0	(0)	2	(40)	0	(0)	1	(16.7)
Female	4	(80)	7	(100)	3	(60)	8	(100)	5	(83.3)
Race/Ethnicity										
Non-Hispanic White	4	(80)	6	(85.7)	5	(100)	4	(50)	6	(100)
Hispanic	1	(20)	1	(14.3)	0	(0)	0	(0)	0	(0)
Asian	0	(0)	0	(0)	0	(0)	2	(25)	0	(0)
Other	0	(0)	0	(0)	0	(0)	2	(25)	0	(0)
Highest education level										
Less than high school	1	(20)	0	(0)	0	(0)	0	(0)	0	(0)
High school graduate	4	(80)	4	(57.2)	0	(0)	0	(0)	1	(16.7)
Bachelor's degree	0	(0)	2	(28.6)	0	(0)	0	(0)	3	(50)
Master's degree	0	(0)	0	(0)	0	(0)	5	(62.5)	2	(33.3)
Doctorate degree	0	(0)	1	(14.3)	5	(100)	3	(37.5)	0	(0)
Care plan meeting Invitation/attendance (Resident/Family)					N/A		N/A		N/A	
Invited	2	(40)	5	(71.4)						
Never invited	2	(40)	1	(14.3)						
Unsure	1	(20)	1	(14.3)						

Table 8: Nursing home stakeholder demographics

	Residents (N=5)		Family (N=7)		Physicians (N=5)		APRNs (N=8)		ADMINs (N=6)	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)
Care plan meeting Invitation/attendance (Health Care Providers)										
Never attended	2	(40)	1	(14.3)	0	(0)	0	(0)	0	(0)
Less than a month ago	2	(40)	1	(14.3)	4	(80)	4	(50)	5	(83.3)
Less than a year ago	0	(0)	4	(57.1)	1	(20)	0	(0)	0	(0)
Over a year ago	0	(0)	0	(0)	0	(0)	4	(50)	0	(0)
Unsure/Missing	1	(20)	1	(14.3)	0	(0)	0	(0)	1	(16.7)
Gerontology Specialty/Cert.	N/A		N/A							
Yes					1	(20)	4	(50)	N/A	----
No					4	(80)	4	(50)	N/A	----
Years of Professional Experience	N/A		N/A							
Mean (SD)					19.6	(11.7)	22.6	(16.0)	15.6	(5.6)

Table 9: Decision-making opportunities and their limitations

Decision-making Opportunities	Limitations
Available options for health care provision: • Which pharmacy to use • Which hospital to be transferred to • Which medications to take	• Only facility-contracted entities can be chosen; generally, there are only 1 or 2 available • Contracted entities must meet & follow certain criteria & policies which few will do for individuals • Extra personal expense is incurred if non-contracted entities are used
Residents can often choose: • Which room to live in or transfer to • Whether to move to hospice services • Whether to be moved to DNR status • Whether to be hospitalized	• Although these were named as resident choices, they were discussed as choices primarily faced and decided by family members or HCPs
Residents can always choose: • To see a HCP	• Timeliness, date of visit, and time of visit are at the convenience of the HCP
Choices to participate in health care activities: • Exercise (physical therapy) • Diet (daily menu, type or consistency) • Medications (type, frequency, compliance) • Diagnostic testing (time, timing) • Hospital admission/transfer • Environment (room décor, music, entertainment)	• Most therapies (PT, meds, testing) are limited by contracts held by the NH with insurance companies, therapy groups, pharmacies, provider time restrictions, facility protocols, federal & state regulations, etc.) • If there is a dietary choice, it is usually small, such as one meal alternative • Residents may be unaware they have choices in these areas • Choices by residents may be ignored unless FM becomes involved • Choices are limited by resident cognitive ability and ability to communicate

Table 10: Dissertation work implications by research project

Implications	Clinical	Research
Review of the Quantitative Literature: *Diabetes management in the nursing home: A systematic review of the literature*	• Improve consistency of T2DM management practice with current clinical practice guidelines; provider education suggested • Improve resident decisional support; increased discussion of guidelines & options suggested • Improve documentation of individualized deviations from clinical practice guidelines	• Determine the association between certain management practices, i.e. glucose monitoring frequency, & specific resident outcomes
Review of the Qualitative Literature: *Involvement of older-aged adults in chronic illness care decisions: A metasynthesis*	• Strengthen productive interactions between residents and health care providers • Question residents regarding preferences for involvement & expected outcomes • Spend more quality time with residents to cultivate trusting relationship	• Explore perceptions of older adults on purpose & expected outcomes of involvement • Investigate association between APRN time spent with residents, & resident outcomes
Ethnographic Pilot Study: *Perceptions and preferences of care voiced by nursing home residents with type 2 diabetes*	• Inform residents of opportunities for involvement in decisions and self-care activities • Provide education regarding available treatment choices and consider resident preferences in plan of care	• Describe opportunities for resident involvement in chronic illness decisions & self-care activities in the NH
Secondary Analysis: *Stakeholder views of nursing home resident involvement in chronic illness decision-making and self-management*	• Initiate support groups within & outside NH to prepare residents/family for admission changes & stressors • Use chronic illness support groups within NHs to provide education & peer support for residents/family • Work with older-aged adults advocacy groups to launch a large-scale media push on purpose, benefits, & goals of NH admissions • Provide education/support sessions HCPs on NH evidence-based practice & goal-setting • Improve effectiveness of care plan meetings by ensuring: purpose is clear to all; convenient timing; residents & providers present	• Examine effects of NH support groups for residents & family prior to & during admission on resident/family quality of life outcomes, health outcomes, & congruence with resident preferences • Describe the relationship between specific care practices of APRNs and resident/family involvement in care & satisfaction with goal attainment, quality of life, & health outcomes

T2DM: Type 2 diabetes mellitus; APRN: advanced practice registered nurse; NH: nursing home

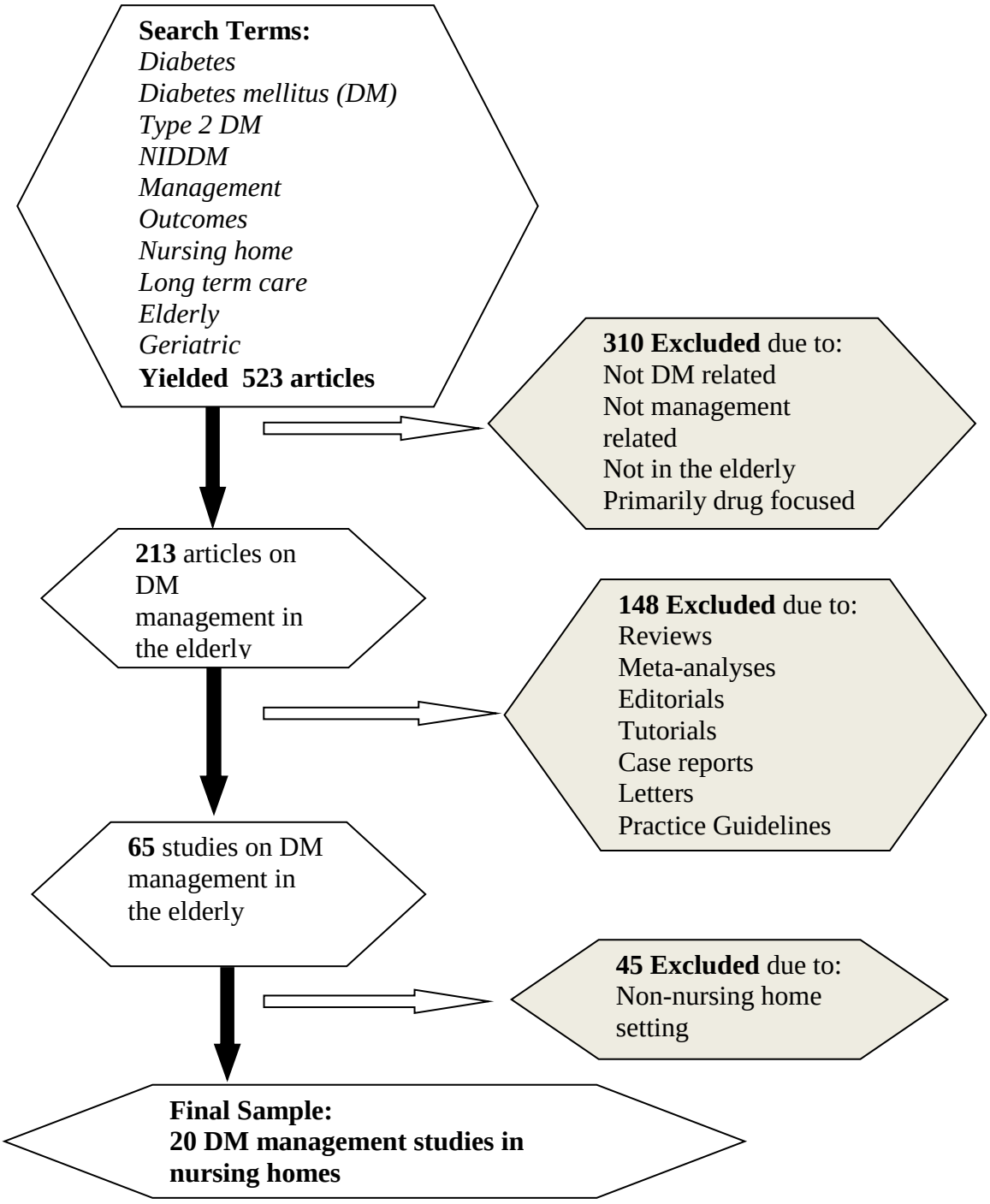

Figure 1: Flow diagram: Systematic exclusion of diabetes management studies

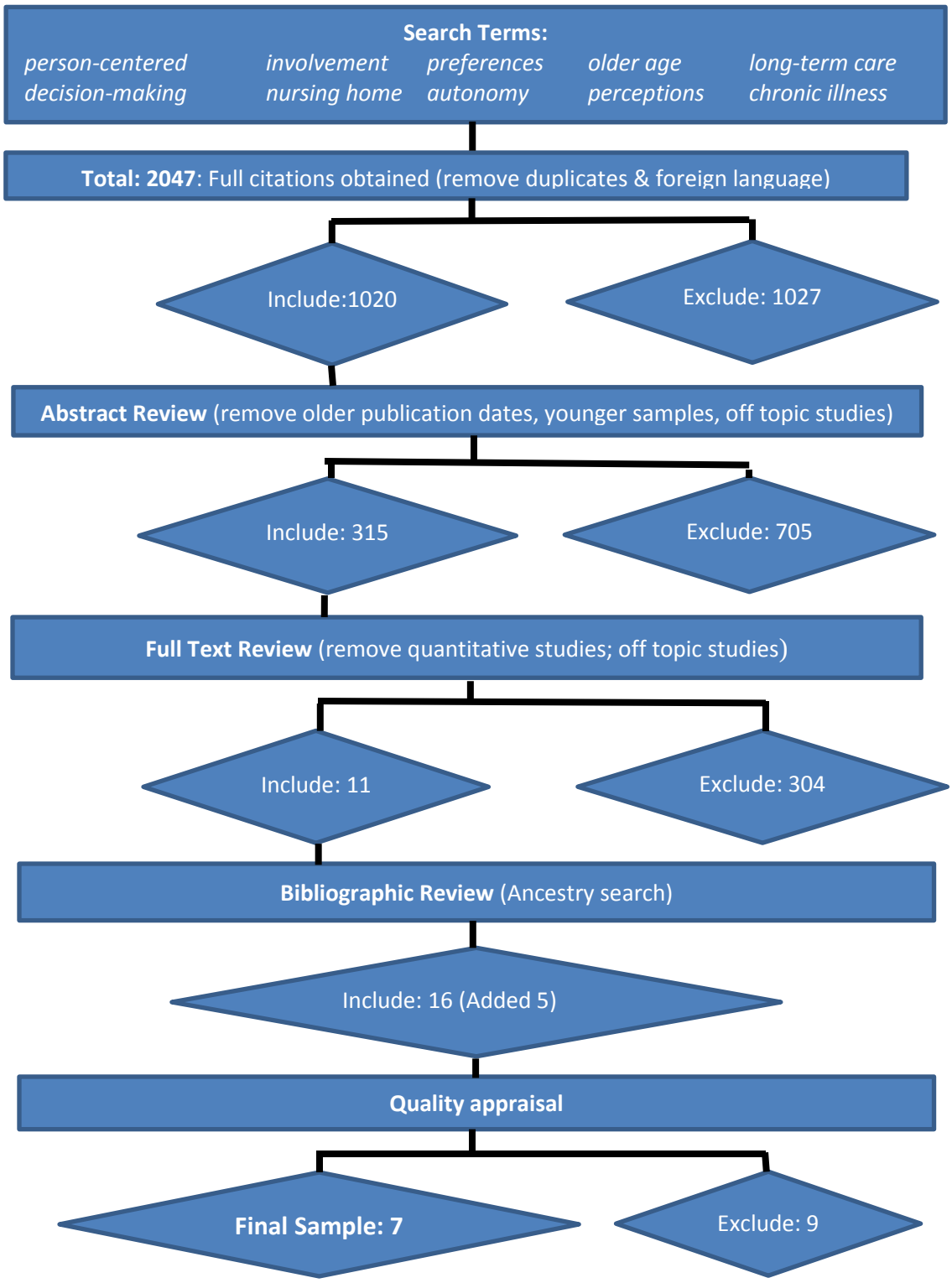

Figure 2: Flow diagram: Systematic exclusion of decision-making studies

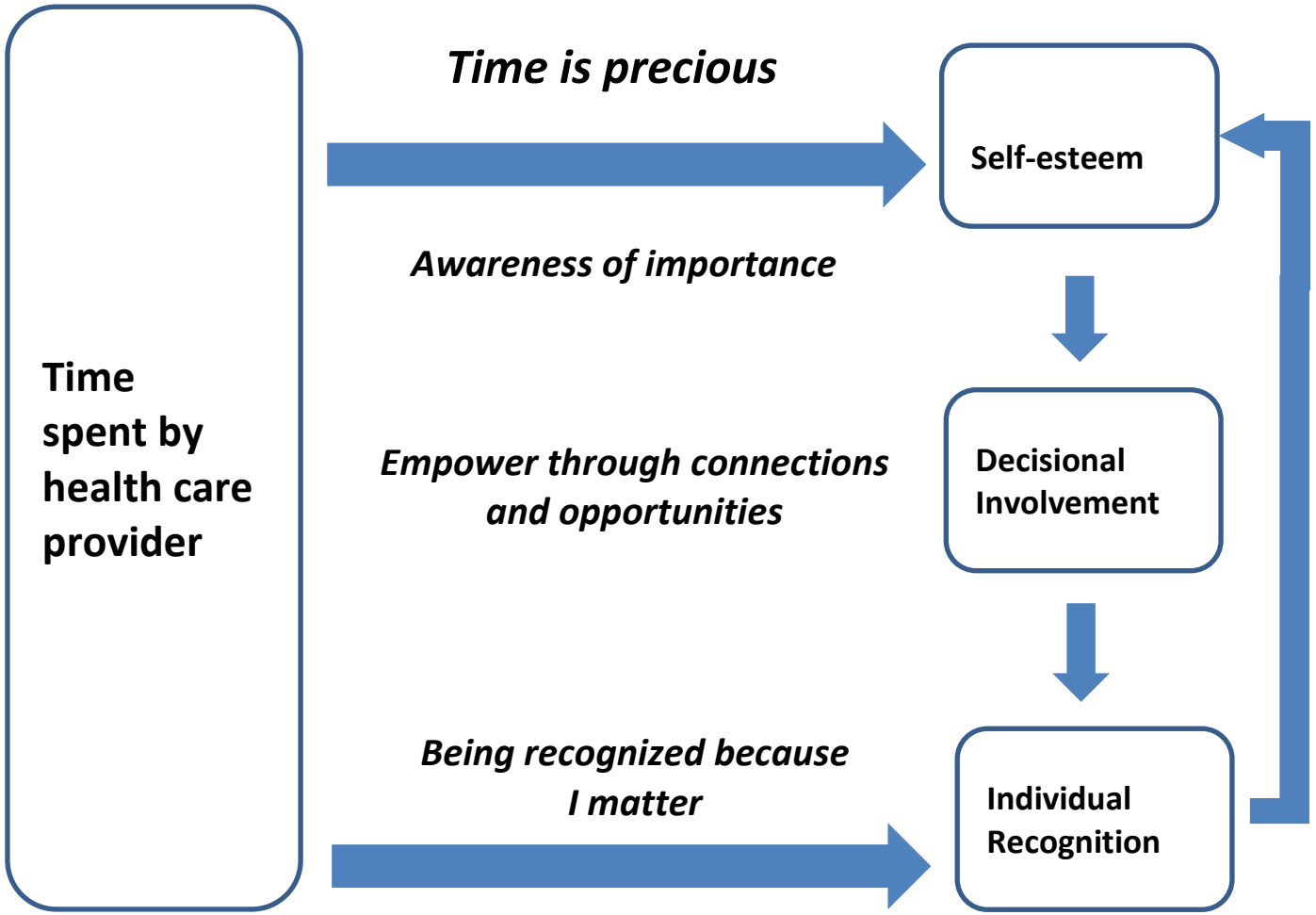

Figure 3: Possible relationships regarding involvement of chronically ill, older-aged patients in health care decisions

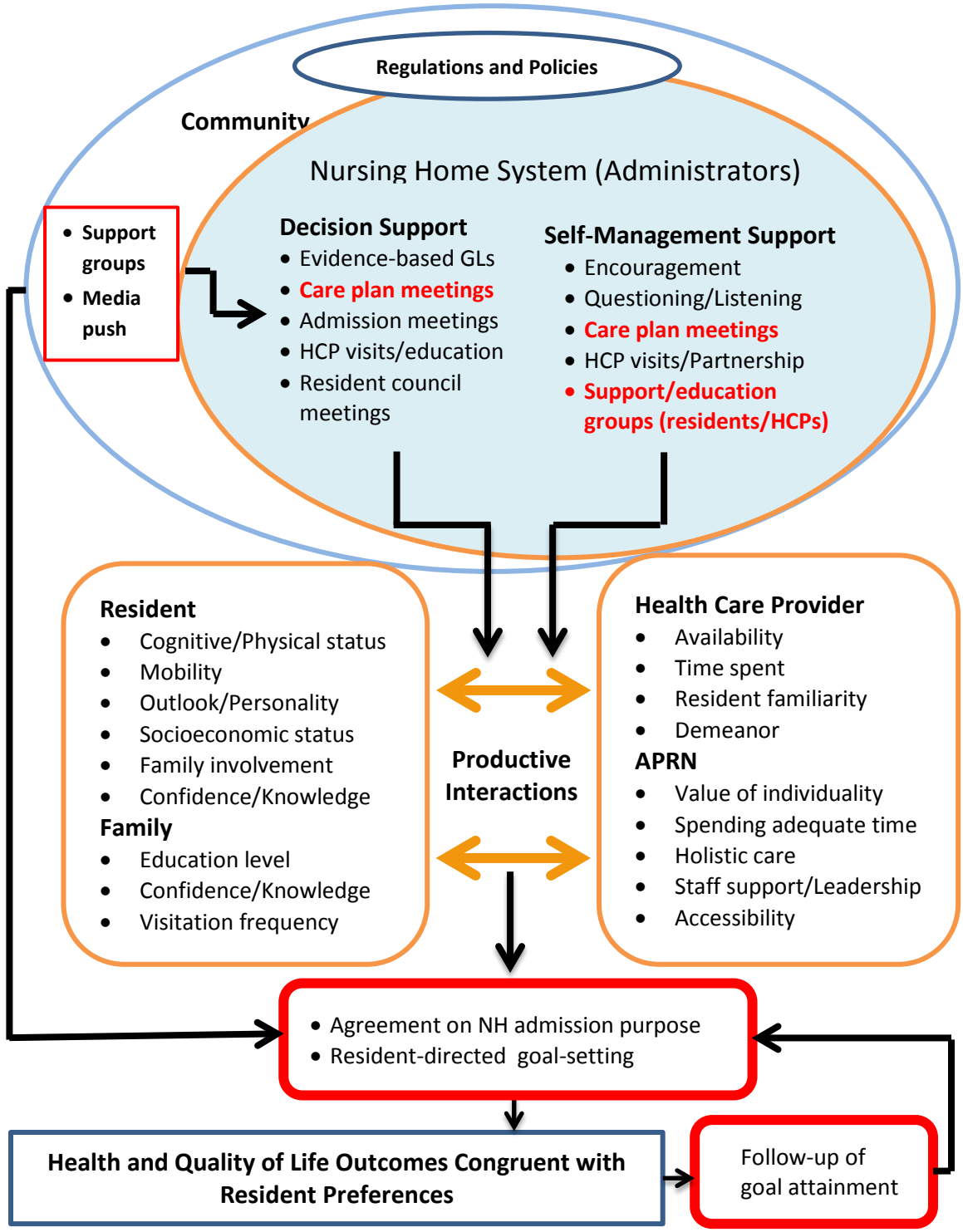

Figure 4: The adapted Chronic Care Model for nursing homes (Modified with permission from Chronic Care Model, The MacColl Institute, ACP-ASIM Journals and Books)

Appendices

APPENDIX A: AMERICAN COLLEGE OF PHYSICIANS LETTER OF PERMISSION

ACP
American College of Physicians
internal medicine | *Doctors for Adults*

ROECP1318154

August 6, 2013

The University of Texas at Austin
6713 Magenta Lane
Austin, TX 78739

Dear Ms. Garcia:

Thank you for your request for electronic format of the following from *Effective Clinical Practice:*

Figure 1: Edward H. Wagner, MD, MPH, Chronic Disease Management: What Will It Take To Improve Care for Chronic Illness? Effective Clinical Practice, Aug/Sept 1998, Vol 1

Permission is granted to republish the preceding material with the understanding that you will give appropriate credit to *Effective Clinical Practice* as the original source of the material. **Any translated version must carry a disclaimer stating that the American College of Physicians is not responsible for the accuracy of the translation.** This permission grants non-exclusive, worldwide rights for this edition / volume in electronic format only. ACP does not grant permission to reproduce entire articles or chapters on the Internet. This letter represents the agreement between ACP and The University of Texas at Austin for request ROECP1318154 and supersedes all prior terms from the requestor. The Annals of Internal Medicine wants to encourage users to go to the original article on the website for scientific integrity, in the event there are retractions and corrections.

Thank you for your interest in *Effective Clinical Practice.* If you have any further questions or would like to discuss the matter further, please contact me at 856-489-8555 or fax 856-489-4999.

Sincerely,

Gina Brown
Permissions Coordinator

APPENDIX B: INSTITUTIONAL REVIEW BOARD DETERMINATION LETTER

OFFICE OF RESEARCH SUPPORT

THE UNIVERSITY OF TEXAS AT AUSTIN

P.O. Box 7426, Austin, Texas 78713 · Mail Code A3200
(512) 471-8871 · FAX (512) 471-8873

FWA # 00002030

Date: 02/04/13

PI: Theresa J Garcia

Dept: Nursing

Title: Person-Centered Chronic Illness Management in the Nursing Home:Opportunities for Resident Involvement

RE: Non Human Subject Research Determination for IRB Protocol Number 2013-01-0104

Dear Theresa J Garcia:

The Office of Research Support (ORS) reviewed the above protocol submission request and determined it did not meet the requirements for human subject research as defined in the Common Rule (45 CFR 46) or FDA Regulations (21 CFR 50 & 56). At this time you are free to begin your research as IRB approval is not necessary. You should retain this letter with the respective research documents as evidence that IRB review and oversight is not required.

If you have any questions contact the ORS by phone at (512) 471-8871 or via e-mail at orsc@uts.cc.utexas.edu.

Sincerely,

James Wilson, Ph.D.
Institutional Review Board Chair

APPENDIX C: PERMISSION FROM SAGE PUBLICATIONS TO REPRINT ARTICLE

RE: Request to re-print my article within my dissertation

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Binur, Michelle <Michelle.Binur@sagepub.com>
Mon 5/6/2013 5:39 PM

To: Garcia, Theresa J;

Dear Garcia,
Thank you for your request. Please consider this e-mail as permission to reprint the material as detailed below in your upcoming dissertation. Please note that this permission does not cover any 3rd party material that may be found within the work. We do ask that you credit the original source, SAGE Publications. Please contact us for any further usage.

Best regards,
Michelle Binur

From: Garcia, Theresa J [mailto:tgarcia@mail.nur.utexas.edu]
Sent: Monday, May 06, 2013 1:18 PM
To: permissions (US)
Subject: Request to re-print my article within my dissertation

Dear Sirs:

I would like to request permission to re-print the following article (of which I am first author):

Diabetes management in the nursing home: a systematic review of the literature.
Garcia TJ, Brown SA
The Diabetes Educator 2011 Mar-Apr, 37(2)167-187.
doi: 10.1177/0145721710395330
http://tde.sagepub.com/content/37/2/167.full

as part of my dissertation to be presented to the faculty of the graduate school of The University of Texas at Austin in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing in July 2013.

Sincerely,

Theresa J. Garcia

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References marked with an asterisk indicate studies included in the systematic literature reviews.

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